TOWARD A THEORY OF PROFESSIONAL SUPPORT FOR PARENTS OF YOUNG ADULT SCHIZOPHRENICS

by

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To the Graduate Council of The University of Utah:

I have read the dissertation of Marilyn [redacted] Park its final form and have found that (1) its format, citations, and bibliographic style are consistent and acceptable; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the Supervisory Committee and is ready for submission to the Graduate School.

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ABSTRACT

This research project is viewed as one step in the development of a theory of professional support for families of chronically mentally ill patients. The clinical problem for this project concerns the reality that parents of young adult schizophrenics have a role as primary caregivers; however, they live with enormous psychological, social, and economic stresses and lack sufficient information and skill to manage symptoms and behaviors effectively. Parents often lack sufficient social support for themselves to alleviate their own distress, which interferes with their ability as caregivers. The above information was available from surveys of members of family support groups. The research problem was that not enough is known about the experience over time of parents who do not tend to join support groups.

In order to suggest a theory of professional support, more specific information on what types of help for which types of problems at what stages of this chronic disease was needed. Professional support by psychiatric mental health nurses and other mental health professionals might mediate distress experienced by

parents and assist parents to provide more effective support for their young adult.

Parents of young adult schizophrenics were asked about their experience with potentially supportive people, including nurses and other professionals. The subjects described experiences in their own words during interviews conducted at their homes. The findings indicate that parents need additional information and professional support in order to be more effective caregivers.

The elements of professional support for parents which are recommended include: (1) a continual professional relationship with parents from the onset of the disease, (2) an esteem for and recognition of parents as a primary caregiver with mutual obligations in the treatment process, and (3) a process of informing parents about the disease, behavior management, and medications which may enable parents to gain more control of stressful situations and become more effective decision-makers.

To Francesca and all of the other parents; and to my family, my committee, and my friends for information and support.

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INTRODUCTION

Schizophrenia now appears to be a collection of chronic diseases of the brain with no known cause or cure. The presentation of the disease often occurs in adolescence or young adulthood, continuing in a chronic course over many years until about the age of 50, when the most active symptoms of the disease appear to go into remission (Tomb, 1984). The manifestations of schizophrenia include disturbances of the form of thought (resulting in reasoning and speech which does not make sense to other persons), of the content of thought (delusions), of perception (hallucinations), of emotions (resulting in inappropriate or flat affect), and of behavior (which may be bizarre, embarrassing, or even dangerous) (p. 20-22). These manifestations of the disease are associated with considerable disruption in a parent/child relationship.

For purposes of this study, the term schizophrenia included schizoaffective disorder and schizophrenic disorders, disorganized, catatonic, paranoid, undifferentiated, and residual types, as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM III) (American Psychiatric Association (APA), 1980). The

duration of symptoms for these chronic diseases must be at least 6 months before the diagnosis can be made.

Theories of schizophrenia as a functional disorder which originates in the early social relationship with the mother and father resulted in considerable research into family interactions and family therapy methods during the 1950s and 1960s (Guerin, 1976; Leff, 1978; McFarlane, 1983). Professionals blamed parents, particularly the mother, for faulty communication processes in early childhood which were thought to cause the development of schizophrenia in a young adult child.

Research during the 1970s and early 1980s resulted in theories that schizophrenic disorders are a collection of phenomenologically-described diseases with their etiology related to genetic factors and their presentation and course affected by psychosocial and biological factors (APA, 1980; Kessler, 1981; Bowers, 1981; Liem, 1981; Torrey, 1983). The interaction among biological, genetic, and psychosocial factors is of considerable interest to researchers and is not well-understood at the present time.

This study was concerned primarily with the psychosocial aspects of schizophrenia and the experience of stress and social support for parents of young adult schizophrenics. Not enough is known about the nature of stressful experiences for parents, what this stress is

doing to their own lives, and what types of social support are available from other people, including professionals, at various stages of the chronic disease might be beneficial to them and to their young adult schizophrenic son or daughter.

For purposes of this research report, stress was defined in terms of upsetting experiences as described by parents of young adults with a schizophrenic or schizoaffective disorder. These stressful experiences were related to having a young adult schizophrenic child specifically, but also to other emotionally upsetting experiences in the environment of the subjects.

Social support was defined for this report as a continual relationship with other persons which leads them to believe that they are held in esteem and are members of groups of people with reciprocal obligations. A supportive relationship is defined as one which fosters other persons' senses that they are in control of their own lives and facilitates motivation toward independence. A supportive relationship allows for both negative and positive feedback which conveys a message that the person is worthwhile, despite any undesirable behaviors.

Professional support was defined for this study as having some of the same characteristics as social support, including a continual relationship with the patient or parent which leads them to feel that they are

respected, worthwhile, and have mutual rights and obligations in the treatment process. Professional support also includes the provision of information which leads the person to understand, to the extent feasible, the disease and the treatment processes. The provision of professional support fosters independence and conveys to the patient or parent a sense that they are in control of the situation to the extent possible. The relationship in professional support provides a climate for both positive and negative feedback about behaviors of the patient or parent and conversely, allows for both positive and negative feedback for professionals about their behavior.

For purposes of this report, the term nurse refers to registered nurses (RNs) who have either a 2, 3, or 4 year education and licensed practical nurses (LPNs) who have completed a 1 year educational program. Psychiatric mental health nurse means nurses who are employed in a hospital psychiatric unit or a community mental health setting. Psychosocial nurse clinician refers to registered nurses with a master's degree in psychiatric or psychosocial nursing who are educationally prepared to be psychotherapists.

Young adult patients between the ages of 18 and 35 who met the diagnostic criteria for the study were referred to as young adults in this report. Individuals

in a treatment role with young adults either in private practice or as direct service employees in a mental health system were referred to as professionals, including, but not limited to, psychiatrists, psychosocial nurse clinicians, psychiatric mental health nurses, social workers, and psychologists. Others who might ordinarily be described as professionals in their respective fields, including friends, relatives, clergy, police, educators, and others were described as other potentially supportive people.

A public hospital for the purpose of this report means a State or Federal hospital which is usually many miles away from the young adult's home community. A private hospital means a hospital psychiatric unit which is usually in the patients' home community, even though it may be partially supported by public funding.

1. PROBLEM

Until the late 1950s in this country, most persons with a schizophrenic disorder were hospitalized for long periods of time, often in large state hospitals. Beginning with chlorpromazine in 1952, neuroleptic drugs became the specific treatment for schizophrenia. Partly as a result of the ability of neuroleptics to control the major behavioral symptoms, most treatment for schizophrenia now occurs in the community. The civil rights movement has given mental patients freedom from unwanted hospitalization except when there is an immediate danger to the patient or someone else, even when hospitalization and involuntary medication would benefit both patients and families. Parents, rather than hospital staff, are now very often the primary care resource for young adults with schizophrenia, whether or not the patient is living at home (Lamb & Oliphant, 1978).

Parents need information and support from professionals to assist them in supporting their young adult with schizophrenia (Anderson, Hogarty, & Reiss, 1980). Hatfield states that the effectiveness of using peers, relatives, and others in the community as social support for families should receive more attention from

professionals (Pepper & Ryglewicz, 1984a, p. 75). The National Institute of Mental Health (NIMH) Community Support Program recognizes the importance of professional influence in developing supportive networks, including families, for the young adult schizophrenic and other chronically mentally ill persons (Mosher & Keith, 1981; Turner & TenHoor, 1978).

Wing (1978) notes that professionals working with schizophrenics and their families need:

> ...a willingness to learn from patients and relatives, who are the people with the essential information on which skilled management must be based. (p. 1337)

Parents and other relatives, as well as patients themselves, have extensive experience with schizophrenia. This study went directly to parents for information about their experience with a schizophrenic young adult child.

The research goal for this study was to learn more about the experience of parents in order to contribute to the development of a theory of professional support for parents of schizophrenics which could be implemented in practice to meet two objectives: (1) reduce distress experienced by parents and (2) assist parents to provide more effective support for their son or daughter.

The clinical problem concerns the reality that parents of young adult schizophrenics have a role as a primary caregiver; however, they often lack sufficient

information and skill to manage the young adult's symptoms and behaviors. Parents frequently lack sufficient social support for themselves to alleviate their own distress. Distress and lack of information and support inhibit the ability of parents to function as effective caregivers.

The research problem was that not enough is known about the experience of parents of young adults with a schizophrenic disorder who do not tend to join family support groups. The fact that parents need help from professionals has been established. More information was needed on the nature of the stresses parents experience, what this experience as parents of a young adult schizophrenic is doing to their own lives, and what types of social support are needed from professionals and other people. In order to suggest a theory of professional support for parents, more specific information on what types of help for which types of problems at what stages of this chronic disease was needed.

This research project was viewed as one step in developing and testing a theory of professional support for families of chronically mentally ill persons. The next step in a continuing study of this problem might be to test the effectiveness of processes of professional support which were suggested as a result of this study.

Nurses have a particularly appropriate background in education and experience which prepares them to be leaders in developing supportive interventions with families of their patients (Fagin, 1970). Nurses have an educational background in both physical and psychosocial treatment and care in health and illness. A 24-hour perspective of the care of a young adult with schizophrenia is part of nursing experience on an inpatient psychiatric unit. Community health and mental health nursing experience prepares nurses to work with families and community resources with an interdisciplinary team to assist schizophrenic patients and their families. Yet there is a lack of systematic processes for the provision of support for parents of young adult schizophrenics by nurses as well as by other professionals (Anich, 1984).

The Young Adult Chronic Patient

Studies have indicated that half of the patients of community mental health centers in this country are between the ages of 18 and 35 (Unger & Anthony, 1984, p. 91). Of these young adult patients, an uninstitutionalized population who are chronically mentally ill with a diagnosis of a schizophrenic or other psychiatric disorder is creating nationwide concern among mental health professionals (Bachrach, 1982; Pepper, & Ryglewicz, 1982, 1984a; Sheets, Prevost, & Reihman, 1982).

Pepper and Ryglewicz include only young adult patients who have been in treatment over a period of at least 2 years in their studies of this population. One study of these young adult chronic patients in a community treatment program described a typical patient as an individual in his 20s who had been diagnosed as having a schizophrenic disorder 5 years previously (Sheets et al., 1982). Other categories of psychiatric diagnoses listed by Pepper and Ryglewicz (1984a, p. 8) for this population of uninstitutionalized young adult patients include affective disorders, personality disorders, and drug-alcohol abuse. The categories are not mutually exclusive, and schizophrenic young adults may have another disorder as well.

These young adult chronic patients have impaired social relationships in the community and often resist traditional treatment modalities from a system not geared to their needs. Pepper and Ryglewicz (1982) found that of these young patients of a mental health center in Rockland, New York, half had never been hospitalized and few of them had been hospitalized for a long period of time.

Schizophrenia first appears as a disease of young adults. Typically, young men with schizophrenia are first diagnosed in their teens or early 20s while young women are often in their 20s or early 30s when they

experience their first noticeable psychotic episode (Tomb, 1984).

Parents' Perception of the Problem

About two million persons are afflicted with schizophrenia in this country (Tomb, 1984). This means that there are approximately four million parents who have been or will be told that their son or daughter suffers from this disease. Parents of young adult schizophrenics in the 1980s face some of the difficult behavioral manifestations of a schizophrenic disorder that would have been handled by hospital personnel before the deinstitutionalization movement. Parents are attempting to cope with some of the same treatment and care problems that have been difficult for professionals, although parents are more emotionally involved and less knowledgeable about the disease processes.

Studies by Hatfield (1983) and Spaniol and Jung (1983) have indicated that parents and other family members have needs for information and support which could be met by professionals but often are not. The respondents in these studies tended to be a select group of people, well-educated mothers with annual incomes over $30,000 who were members of the National Alliance for the Mentally Ill (NAMI). Members of NAMI tend to be those who are very concerned about their family members and

often dissatisfied with treatment systems (Unger & Anthony, 1984).

The Spaniol and Jung survey asked parents about their most important source of support. The most frequent source of support reported was a self-help or support group (32.6%), followed by mental health professionals (19.9%) and spouse (17%). Spaniol and Jung also asked this group of people what had been most helpful to them in gaining information about the mental illness of their son or daughter. A support group was again reported to be most helpful (30.5%). Reading materials or films were reported as most helpful by 24.1%, while mental health professionals and trial-and-error learning were each reported as most helpful by 18.4% of the respondents. Listed most frequently as their most important needs were practical advice (24.1%), information about the illness (21.2%), and treatment coordination (17.5%) (p. 44). A majority (53.1%) of the respondents indicated that mental health professionals have not helped them to understand their family member's illness, with 33.1% reporting a generally adequate understanding, and 8.1% a very adequate understanding (p. 44).

Parents of schizophrenics have needs similar to the needs of other parents whose children have serious, chronic illnesses. Hatfield (1978) cites a study by

Debuskey which indicates that families of children with illnesses such as heart diseases, cystic fibrosis, and leukemia suffer "shock, fear, guilt, and confusion" (p. 355). She notes that recommendations in another study by Travis are that the seriously ill child's parents need to receive attention from treatment personnel because of their emotional, economic, and physical needs which are related to the child's illness. Studies indicate that parents of schizophrenics often experience a sense of burden, depression, grief, and frustration (Spaniol & Jung, 1983).

Lamb (1982) feels that mental health professionals should respond more effectively to these expressed needs of families:

> Families of schizophrenics have received too little help from mental health professionals, even though in many cases families are the real primary care agents for long term, severely disabled patients. (Lamb, 1982, p. 104)

Professionals need more information about how to provide support for families of schizophrenics. The family support groups may be one important source of social support for parents. Parents who do not belong to family support groups may be missing an important source of social support. This study asked parents who do not belong to family support groups (as well as those who do) what support from other people is helpful or not helpful and what types of support may be needed in order to cope

with the stresses of having a young adult schizophrenic child.

The studies reported by Hatfield, Spaniol and Jung, and Unger and Anthony were all surveys of members of NAMI affiliates (local family support groups). Parents and other family members tend to join NAMI affiliates out of concern for a seriously ill family member and a dissatisfaction with available treatment resources. The respondents tended to be well-educated professional and business people. Thus, the subjects in these studies were a biased sample of individuals who were critical of the lack of availability of appropriate mental health treatment and who had a higher than average socioeconomic status.

The present study was designed to learn about stressful experiences and needs for social support from parents who do not tend to join family support groups. The method differed from previous studies in that data were derived directly from face to face interviews with a sample of parents. The subjects differed from those in previously reported studies in several important ways. They had a lower average income, a lower educational level, and few were active members of a family support group. The data were in parents' own words rather than responses to preselected categories on a mailed questionnaire.

2. THEORIES OF SCHIZOPHRENIA AND THE FAMILY

Theories of schizophrenia and the family are still evolving. Kessler (1981) points out that the tendency to view only one aspect of available information as dogma had a polarizing effect in the past, bringing out the old "nature-nurture" controversies. For this study, genetic, biochemical, and psychosocial theories were reviewed. Related research and therapy methods are made a part of the discussion.

Genetic Theories

Kessler (1981) reviewed genetic studies of schizophrenia, including independent family, twin, and adoption studies. All of the studies point to the conclusion that persons with a family history of schizophrenia are more likely to develop the disease. About 1% of the general population worldwide is at risk for developing schizophrenia (Tomb, 1984). Up to 50% of monozygotic twins of schizophrenics also develop the disease, whether or not the same parents raise the twins. Dyzygotic twins and siblings of a schizophrenic person have about a 10% chance of developing the disease. An important point is

that all monozygotic twins of a schizophrenic do not develop schizophrenia, indicating that genetics alone does not explain the incidence of the disease.

Studies of biological and adoptive families of both schizophrenic young people and nonschizophrenic controls have generally been credited with providing clear evidence of a genetic etiological factor in schizophrenia. Lidz and Blatt (1983) criticized adoption studies carried out by Kety, Rosenthal, and Wender (1978) and others. Studies were done largely by examining historical data. Lidz and Blatt concluded that there "may" be a genetic factor in the etiology of schizophrenia. However, they believed that family environment was not ruled out as a cause by the studies cited because of the lack of sufficient direct study of the adoptees and their families, small samples in various categories, and other methodological problems.

Biochemical Theories

Bowers (1981) reviewed the evidence that biochemical changes influence both the presentation and the course of schizophrenic disorders. The most obvious positive evidence is that neuroleptic medication controls the major symptoms of the disease in most cases. The "dopamine hypothesis" of schizophrenia is that there is an excess of the neurotransmitter, dopamine, available in

the brain. Neuroleptic drugs, by interfering with the "reuptake" of dopamine, lower the available amount in the brain neuron synapses, with resulting clinical improvement for most persons with schizophrenia. Investigations are continuing on the relationships between biological and clinical states such as loss of affect, poor social development, and psychotic symptoms.

Psychodynamic and Family System Theories

Bertalanffy (1974), a biologist, applied system theory to the study of human behavior in the early 1950s. He viewed this contribution as part of a worldwide evolution in thinking which had seen all fields of science move from a focus on analytical, cause and effect relationships to new ways of thinking. Newer views of science include normative and system approaches in which the whole of any phenomena is seen as including interrelating factors more complex than the sum of the parts.

During the early 1950s, general systems theory was combined with psychodynamic theory to explain individual behavior in the context of the family by American theorists addressing the phenomena of schizophrenia (McFarlane, 1983). Family therapy was developed primarily out of the attempt to understand schizophrenia.

Psychoanalytic theory was perhaps the most prominent theory in psychiatry during the 1950s in the United

States. The "internalized family" was the focus of psychoanalytic therapy and the "real family" was not included in the treatment process (Mendel, 1975). Mendel advocates the inclusion of the real family in the psychotherapeutic process with a schizophrenic:

> The patient requires help in managing his relationships with his family and the family may provide a great deal of support and help in the task of increasing the patient's ability to function. (p. 156)

Beels and McFarlane (1982) divided professionals involved in family research and treatment of schizophrenia into roughly two groups: (1) the "idealogical" family therapists of the 1950s and 1960s in the United States, who believed that the pathology was within family communication processes and (2) the "more pragmatic" researchers of the seventies and early eighties in England and the United States who believed that schizophrenia had biological and genetic origins, but noticed that the family seemed to have a profound effect on the course of the illness. The latter group of researchers/family therapists will be discussed later as biopsychosocial theorists.

Of the former group of researchers/family therapists, three major theories were developed: direct family causation (Lidz, 1973), double-bind (Bateson, Jackson, Haley, & Weakland, 1956), and communication deviance (Wynne, 1981).

Lidz (1968) attributed a direct parental cause to the development of schizophrenia. Lidz, Cornelison, Terry, and Fleck (1958), following Fromm-Reichman's classic description of a "schizophrenogenic mother" (1948), described other characteristics found in parents of schizophrenics in terms of "transmission of irrationality." Lidz also described "marital skew" and "marital schizm" from studies of the family environments of schizophrenics.

Lidz (1973) stated that "neglect of the family has been a major cause of therapeutic failure" (p. 118). He advised professionals not to treat families as "villains" as "their noxious influences...were not malevolent." He also recommended encouraging family groups for interchange of ideas and comments among family members.

Bateson et al. (1956) developed a theory of schizophrenia featuring the <u>double-bind</u> concept whereby the parents put their children in difficult situations by giving them opposing verbal and nonverbal messages at the same time. This faulty communication process was seen as a cause of schizophrenia. Research on this theory was done by clinical studies of patients, not families. Double-bind communication has since been identified in families with no schizophrenia.

Haley (1976, 1980), one of the original authors of the double-bind theory, came to believe that a family-

causation theory is not useful. He developed a theory of "hierarchical incongruity" in which the power of parents to control behaviors in the family needs to be restored in order for a family with a disturbed young person to function adequately. Rather than advocating therapy to correct the dysfunctional parent, he made parents an ally in the treatment process, working with them in a practical way to develop strategies for regaining control of family situations and dealing with relapses of undesirable behaviors of the young adult. The goal of therapy was to approximate a more normal family unit, so that the young, disturbed member could reach a more optimal level of functioning and eventually be able to "leave home."

Haley believed that labeling is not helpful. He avoided the medical model of schizophrenia as a disease, but he reported results which have reduced rehospitalization of young people with psychotic symptoms of schizophrenia. This research on recidivism should be taken seriously by professionals attempting to treat young adult schizophrenics (Beels & McFarlane, 1982).

Wynne (1981) described communication deviance (CD) from extensive research begun in the 1960s using Rorschach and TAT tests with individuals having a schizophrenic family member. He and his colleagues found that incidents of CD occurred more often in families with a schizophrenic member than in those with no

schizophrenic family member. Wynne described CD as a dimension of interpersonal relationships. Singer and others identified 32 categories of CD in parents of schizophrenics (Singer, Wynne, & Toohey, 1978). Wynne (1981) viewed CD in parents of schizophrenics as a precursor of schizophrenia, although CD was not specific to these individuals (CD was found to a lesser extent in families with neurotic, borderline, and "normal" children). He noted that others have suggested that parents develop communication disorders in response to the schizophrenia of their child, but he believed that the evidence points to a relationship in the other direction.

Although he implicated CD in the development of schizophrenia, Wynne (1983) believed that family therapy based on a combination of systems and psychodynamic theory should not be used as the sole treatment method for schizophrenics.

Leff (1978) reviewed family research from the 1950s to the 1970s and noted that early enthusiasm for family therapy based on a family causation theory of schizophrenia turned to pessimism and that

> ...it is clear that if there are environmental abnormalities in the families of schizophrenics, they differ only in degree and not in kind from those found in families with normal offspring and offspring with other psychiatric disorders. (p. 220)

Labeling Theory and the Family

Labeling theorists have said, in effect, that society imposes labels on persons who are deemed to be deviant in some way. The label (e. g., schizophrenia) then determines how those persons are viewed by society and by themselves, adversely affecting their lives. Szasz (1974), a psychiatrist, agreed with labeling theorists and wrote a book on the subject, The Myth of Mental Illness. He believed that labels for mental illness were detrimental to the person so labeled.

A controversy over the potential usefulness of a diagnosis in planning treatment versus the possible social harm attributed to the diagnostic label has been the subject of some heated debate in nursing as well as in other fields (Wilson & Plumly, 1984). As a result, some professionals have been reluctant to label an individual as schizophrenic, believing that the label itself becomes a problem. Haley (1976) asserted that:

> To label...an adult as...a "schizophrenic," means that one is participating in the creation of a problem in such a way that change may be made more difficult. (p. 3)

There is a continuing debate in the field of sociology (Gove, 1982; Scheff, 1966, 1975) about the labeling theory of mental illness. At one end of the continuum, labeling theorists such as Scheff agreed with Szasz (1974) that mental illness is a myth imposed on an

individual by the social environment. Gove took a more moderate view. He contended that, although sociologists lean toward a labeling theory of schizophrenia and other disorders, labeling theory is out of date, invalid, and has not kept pace with substantial changes in the field of psychiatry (1982). Gove believed that psychiatry benefited from the debate and gave more attention to social, as well as biological and intrapsychic concerns about mental illness in the latest diagnostic classification system. American psychiatry, in collaboration with other disciplines, developed a phenomenologically-based classification system, the DSM III (APA, 1980).

Debate on the DSM III classification system has continued in the field of psychiatry (Klerman, Vaillant, Spitzer, & Michels, 1984). Some psychiatrists held that the DSM III classification system ignored cultural and developmental factors in mental illness. Others believed that the practical value of DSM III in terms of relating diagnosis to prescription of treatment outweighed the disadvantages. Most agree that a "DSM IV" should be developed to adjust to changes in the state of the art, such as international agreement on the classification of psychiatric disorders and biological, psychosocial, and pharmacological research on mental illness.

There are differences among professionals and parents in their view of the meaning of the diagnostic

label in schizophrenia. Many professionals would agree with Vaillant (Klerman et al., 1984) that schizophrenia should be defined as a reaction pattern and not a disease entity (p. 543). Published reports of meetings of members of NAMI (Shetler, 1982) made it clear that these parents were committed to a label of schizophrenia as a disease entity, with hope for research to make medical cure a future reality. These same parents also rejected the notion of a social cause of schizophrenia, some of them resentful about having been labeled themselves as schizophrenogenic mothers. They preferred to hear about biological research.

No studies were found about parents' perception of a label for their young adult's schizophrenic disorder. In this study, parents' perception of the label, schizophrenia, was explored.

Biopsychosocial Theories

Stress

In 1936, Selye (1973) first described "stress" as the phenomena of the body's biological response to nonspecific "stressors" such as trauma, infection, X-rays, or nervous stimuli. He spent many years in Canada studying the concept of stress as a contributor to the development of physiological disease. Diseases such as gastric ulcers were described by Selye as "diseases of

adaptation" and stress was described as "the consequence of the rate of wear and tear in a biological system" (Tanner, 1960, p. 68). Experimental physiololgy was the setting for studies of induced stress in animals. A typical experiment was to induce myocardial infarction in animals who had been pretreated with certain sodium salts and corticoids (which had been identified as precursors) by subjecting the animal to a stressor such as a sudden, cold bath.

An important conclusion from Selye's research is that most diseases have various, interacting causal factors rather than a specific pathogen, as had been thought previously. Another important result is the development of specific treatments such as beta blockers, which protect the heart from stress, helping to prevent myocardial infarction.

In the field of sociology, research on psychosocial factors which produce stress has been carried on for many years in many different countries (Kaplan, 1983). Most of the research has focused on either the occurrence of major life events or on ongoing interpersonal relationships.

Psychosocial stress is a particularly important concept in the treatment of schizophrenia, as schizophrenics have difficulty screening out any stimuli from their environment or from intrusive thoughts, such as

hallucinations (Tomb, 1984). This inability to prioritize incoming stimuli makes the individual acutely sensitive to stressful factors in the environment (Anderson, 1983; Brown, Birley, & Wing, 1972; Brown, Carstairs, & Topping, 1958; Tarrier, Vaughn, Lader, & Leff, 1979; Wing, 1978).

This study was designed to identify and describe stress which is experienced by parents of young adults with schizophrenia. Upsetting experiences for parents might be related to unpredictable, bizarre, or violent behaviors or personality changes. Reactions of other people to the problems of having a schizophrenic young adult might be upsetting to parents. Parents might have personal experiences such as a loss of ability to control stressful family situations, a lowering of self-esteem, or a feeling of failure as a parent. Lack of information about the cause of the behavior or what to do about it may be very upsetting. Parents may be experiencing changes in their own lives because of the schizophrenia, such as having to take care of a young adult they expected to be independent at the age of 25 or 30, experiencing marital problems, or having their social and vocational lives restricted. Not knowing where to go for help for the baffling behaviors of their young adult could be very stressful.

The nature of stressful experiences such as these in the lives of a sample of parents of young adult schizophrenics were described in this study. The stressful experiences were related to the available social support in their environment.

Social Support

Social support has been found to be a mediator of stress (Cobb, 1976; Haggerty, 1980). An important source of social support for young adult schizophrenics is their parents. Parents have the capacity to either aggravate symptoms of schizophrenia or provide social support which can mediate stressful factors in the environment and facilitate optimal adjustment to the schizophrenic disorder.

Social support is difficult to define, perhaps because what is perceived as "supportive" differs from situation to situation and person to person. Two theoretical positions were identified from the literature (Dimond & Jones, 1983). Weiss (1969, 1974) studied two groups of people, women who had moved to new locations with their husbands and people who had been divorced or separated from a spouse, and concluded that support is needed from both a close, intimate relationship, such as marriage, and from friends who convey a feeling that they will fulfill the subject's needs on an ongoing,

sustaining basis. Cobb (1976) formulated a definition of social support as information leading the subject to believe that he is esteemed and a member of a network of mutual obligations which will encourage independent thinking and action on the part of the subject.

The concept of social support for parents was addressed in this study. Parents were asked to describe stressful experiences with their schizophrenic child in relation to their experience with potentially supportive people, including professionals. The concepts of stress and social support were used to develop a theoretical model of professional support for parents.

Dimensions of Social Support

Four relevant dimensions of social support were conceptualized for this research project: size, content, timing, and intensity. The dimension of intensity will be discussed in relation to measures of expressed emotion.

Size. Social networks have been studied as groups of people to whom an individual can turn for support to mediate the effects of stressful life events. Individuals with schizophrenia tend to have a comparatively small social network, usually family members and often including mental health professionals (Beels, Gutwirth, Berkeley, & Struening, 1984). Beels (1978) investigated

the effects of social networks on the course of schizophrenia by comparing the experience of schizophrenia to research results of various community treatment programs. He concluded that patients do better when both parents and patient have mutually satisfying relationships outside of the family and that professionals should encourage the development of peer support and family support groups to expand the size of the network of supportive groups of people.

This study gained information about the effect of having a young adult schizophrenic child on the size of social support networks for parents. The amount of social support received from members of various groups of potentially supportive people was described by a sample of parents.

Content. Among members of potentially supportive groups, the attitude toward schizophrenia is important (Beels et al., 1984). For example, the attitude of a relative who believes that the young adult is exhibiting willful, obnoxious behavior may be very different from the attitude of a relative who views the behavior as manifestations of a disease. The differences might be exhibited by blaming the parent in the former example versus providing social support which could alleviate parent's distress in the latter example.

The culture of the family is important in shaping the attitudes of its members toward the phenomena of schizophrenia. The attitudes of potentially supportive people, including professionals, and the cultural environment of the subjects were described by parents in relation to stressful experiences with a young adult schizophprenic child.

Timing. In her research on the experience of dying patients, Ross (1969) found that the amount and kind of social support needed over various stages of the process of dying differed and that sensitivity on the part of professionals for this process was often lacking. She asked dying patients to describe their experience. One patient who was perceived by hospital staff to be "hostile" was left alone at a time when the patient felt she desperately needed people close by.

Wynne (1983) emphasized an early, supportive approach to families by professionals. He noted that an unfortunate tendency of some staff on an inpatient unit to convey the message to families that "the staff members primarily want the family off their collective back" (p. 255) makes later development of supportive relationships with the family extremely difficult. He described a "closure" or a cutting-off of the opportunity to relate successfully when the family is not contacted immediately upon the patient's admission to an inpatient unit. The

family may feel ostracized or may reorganize themselves emotionally without the patient.

This study examined potential social support for parents at various time periods. Stressful experiences at various stages of the schizophrenic disorder of their young adult were described by parents in relation to the amount and types of social support available at that time.

Expressed Emotion

The intensity of the stress is particularly important in the relationship of young adult schizophrenics and their parents. Studies in England and the United States have associated intense emotional overinvolvement by families with recurrence of flagrant symptoms which resulted in rehospitalization of a schizophrenic family member (Brown et al., 1958; Brown et al. 1972; Vaughn & Leff, 1976). An index of this stress factor has been designated as expressed emotion (EE). Research has indicated that criticism and marked emotional overinvolvement on the part of a relative coupled with a high sensitivity to the environment of a person with schizophrenia tends to cause a relapse of the illness. The overinvolvement by parents is described as "excessive anxiety, overconcern, or overprotectiveness toward the patient" (Vaughn & Leff, 1976, p. 125).

The measure of EE involves a rather complicated rating of incidents of criticism, hostility, or over-involvement with the patient in an interview conducted with the family member at the time of hospitalization of the patient.

Researchers have concluded that schizophrenic individuals seem to respond best to a supportive environment in which intensive emotional overinvolvement of their parents and others close to them is kept to a minimum (as long as careful prescription of neuroleptic medications receives adequate attention) (Falloon, Boyd, McGill, Razani, Moss, & Gilderman, 1982; Vaughn & Leff, 1976; Vaughn, Snyder, Jones, Freeman, & Falloon, 1984; Wing, 1978).

The level of intensity of expressed emotion in families may be related to the amount of stress for parents and the level of social support needed for parents from other people, including professionals, to mediate stress. The best information on social support can be obtained from studies of the <u>experience</u> of families, other caretakers, and the patients themselves (Beels et al., 1984). This study will gain information on the dimensions of social support in the experience of a sample of parents of young adult schizophrenics.

Related Research

Psychoeducational Approaches

The research on EE as a precipitant of exacerbation and rehospitalization led to the development and testing of models of psychoeducational support for families of schizophrenics. Anderson, Hogarty, and Reiss (1980) were involved in a long-term program of research studying the effects on the course of the illness of providing information and support for families. Subjects were mostly parents of young adult schizophrenics. The experimental group was assisted by professionals to "de-intensify" their relationship with the patient in response to research on the negative effects of high levels of EE. A control group of patients was maintained on medication management. The goal of the program was to:

> increase the predictability and stability of the family environment by decreasing family members' anxiety about the patient and increasing their self-confidence, knowledge about the illness, and ability to react constructively to the patient. (p. 492)

Results indicate that families receiving this type of psychoeducational support can be maintained in the community, even with severely ill schizophrenic family members. An experimental design compared the effectiveness of medication management alone to the experimental psychoeducational approaches with the family along with

medication management. Indications are that the experimental treatment was more effective.

Rosenthal, Krakoff, and Panepinto (1981) developed a psychoeducational program for families of schizophrenics as a way of providing service for groups of people in response to a need in their mental health center. The program was based on biological and psychosocial theories of schizophrenia and suggested specific strategies for parents to manage their young adult schizophrenics more effectively. A series of classes on various topics adjusted to meet individual needs plus an ongoing support group by professionals resulted in parents solving their own problems well enough to help others with the development of a mental health advocacy group.

A family management program which featured home visits by professionals (in this case, psychiatrists, psychologists, and social workers) was reported by Falloon et al. (1982). The experimental group of families, which included the patient, was provided with individualized education and supportive behavioral intervention strategies in their homes. Schizophrenic patients in the control group were seen in office therapy. Careful attention was paid to optimum doses of neuroleptic medication for patients in both groups. The family management patients showed statistically significant advantages in measures of rehospitalizations and

symptom remissions (p. 1439). This study suggested that social support for the family by knowledgeable professionals was a positive factor in treatment outcome for schizophrenics.

Further research (Vaughn et al., 1984) indicated that psychoeducational family intervention was needed if schizophrenic patients were to be successfully managed in a home environment where "EE" was relatively high. Maintenance therapy, alone, was not enough. This series of research studies combined both English and American researchers and subjects.

Psychoeducational groups which combined both "Low EE" and "High EE" relatives of patients have shown that the low EE family members apparently assist the high EE members to lower their EE index (Berkowitz, Eberlein-Fries, Kuipers, & Leff, 1984). An important attitude difference was noted in the two groups of family members. The low EE relatives tended to view their schizophrenic family member as having a "legitimate illness" and the high EE members tended to view difficult behavior as within the patient's control and as "deliberate and malicious" (p. 418).

A psychoeducational model of family <u>support</u>, rather than a psychodynamic model of family <u>treatment</u>, became the focus of intervention with families of schizophrenics in the 1980s. Advocates for a psychoeducational model

have concluded that schizophrenic individuals seem to respond best to a supportive environment in which intense emotional overinvolvement of their parents and others close to them is kept to a minimum, as long as careful prescription of antipsychotic medication receives adequate attention. The psychoeducational approaches were accomplished with groups of family members who attended educative sessions, except for the Falloon et al. studies which involved home visits by mental health professionals. While positive results were indicated for all approaches, the present study was needed to gain more information about the experience of parents in relation to the need for professional support as a continual process.

Nursing Support for Families

Evolution of professional programs to assist persons with schizophrenia and their families has paralleled development of theories of the disease itself. Of interest to this study is the evolution of the professional nursing role in the treatment of the family with a schizophrenic member.

During the 1960s, public health nurses (the newer term is community health nurses) were visiting previously hospitalized psychiatric patients and their families in their homes. A 1961 study (Pasamanick, Scarpetti, &

Dinitz, 1967) found that community health nurses, as the primary treatment agents, were able to stabilize mentally ill individuals at home with their families as long as the patients remained on medication. The control group patients were either hospitalized or returned to home care on placebos.

The Pasamanick et al. study indicates that nursing support was a positive factor in the successful adjustment of mentally ill patients living with their families.

> The public health nurses were the principal treatment agents: their regular home visits, in-depth knowledge of the clients and families, and, most importantly, their relationships with them were the critical home care success ingredients. (Davis, Dintz, & Pasamanick, 1972, p. 376-377)

However, a follow-up study 5 years later when nurses were no longer providing this specific support (after funding for the initial study had been discontinued) showed few significant differences in the patient groups. Those who had improved or stabilized earlier had regressed, indicating that some form of <u>continued</u> support for these patients and their families in the community is essential if relapse is to be prevented (Davis et al., 1972).

A 1982 report out of India (Pai & Kapur) described an experimental design set up at the National Institute of Mental Health and Neurosciences in Bangalore which compared nursing intervention in the home to hospital treatment. Measures were of burden on the family, social

dysfunction of the schizophrenic patient, and the patient's clinical psychopathology over a 6-month period. The patients were all suffering from a first episode of schizophrenia and were assigned alternately to psychiatric hospital treatment with outpatient follow-up or to remain with their families and receive counseling for themselves and their families by a nurse. The three dimensions studied were found to be highly correlated. The home treatment by the nurse was found to be significantly superior to hospitalization on measures of all three dimensions of clinical psychopathology, social dysfunction, and burden on the family.

Research results indicate that home visits by community health nurses were effective in stabilizing schizophrenic patients at home with their families. Maintenance on medication and supportive relationships with the family were reported to be factors in positive outcomes.

Anich (1984) studied families of chronically mentally ill (CMI) individuals who were members of a local family support group in Salt Lake City. She investigated needs and coping strategies used by family members, using a card-sort research technique, and found that family members had needs and coping problems which could be helped by professionals. She concluded that nurses and others <u>should</u> make an effort to maintain the

family as a supportive system for the patient.

Anich recommended that several things be taken into consideration in future studies, including client's place of residence and length of illness. She also recommended looking at the differing needs and coping abilities of family members over time since the diagnosis. The present study was conducted with a sample of parents, most of whom were not members of a family support group. The place of residence and the length of illness was addressed, with attention to the differing experiences of stress and social support over time.

Summary

As the deinstitutionalization of state hospital patients began in the 1950s, many schizophrenic patients went home to live with their families and were rehospitalized whenever they became very upset. In the 1960s, mental patients began to be given their right to be free from hospitalization and parents became a primary source of care for young adult schizophrenics.

Psychodynamic and system theories were combined in the 1940s and 1950s to conclude that the origin of schizophrenia occurs in faulty social interactions in early childhood with parents, particularly the mother. Researchers have now become interested in biological and biopsychosocial factors which may affect the presentation

and clinical course of schizophrenia. Medication is helpful in almost all cases of schizophrenia. Psychoeducational approaches and nursing intervention in the home have been found to be helpful to families with schizophrenic members.

Surveys of members of family support groups indicated that they are not satisfied with the amount of support and information provided to themselves by professionals. Not enough information is available about stress and social support in the experience of parents who do not tend to join family support groups. Information from the perspective of parents about their stressful experiences over time with their young adult in relation to the social support available from professionals and other people was the focus of this study in order to contribute to a theory of professional support for parents.

3. METHODOLOGY

Introduction

This research project was designed to be one step in the development of a theory of professional support for parents of schizophrenics. The purpose of the study was to discover useful information, not to verify information already available.

The clinical problem presented for this study was that many parents of young adult schizophrenics lack sufficient information and skill to manage their adult children's symptoms and behaviors effectively, although parents often have a role as a primary caregiver. Parents frequently lack sufficient social support to alleviate their own distress, which interferes with their ability as caregivers.

The research problem was that not enough is known about the experience of parents of young adults with a schizophrenic disorder who do not tend to join family support groups. The specific aims of the research study were to describe the nature of stresses experienced by parents and their perceptions about the types of social support and information available to them, and to suggest a theory of professional support for parents.

The phenomena of interest for data collection included the nature of stresses experienced by parents over time beginning with the diagnosis of a schizophrenic disorder of their son or daughter and the relationship of these stressful experiences to potentially supportive people. Information about the parents' perception of types of assistance and support available or needed were obtained about three categories of potentially supportive people: (1) professionals, (2) family and friends, and (3) other community groups, for example, churches, neighborhoods, social groups, public and private agencies, employers, or family support groups.

A method of naturalistic inquiry was chosen as most appropriate to gain information about the experiences and perceptions of parents of young adult schizophrenics. Naturalistic inquiry, in contrast to more traditional methods, aims toward examination of the phenomena of an experience in its natural setting rather than reducing phenomena to preselected categories which are examined in a controlled research setting. The phenomena of interest for this study were described from the perspective of the parents.

The experience over time of having a young adult schizophrenic child could be described as a dynamic process, rather than a series of static events. A

naturalistic inquiry method captures data about a process which would be missed with more traditional methods.

The philosophical base for naturalistic inquiry is phenomenology, which describes reality in a given situation as whatever it is perceived to be (Guba, 1978). Research based on a phenomenological perspective is concerned with understanding the meaning of an experience.

The naturalistic method was considered in terms of its appropriateness for nursing research. A related method, a phenomenological approach, has been recommended for nursing research by Davis (1973), Oiler (1982), and Omery (1983). The aim of a phenomenological approach is to "describe experience as it is lived" (Oiler, 1982, p. 178). This approach is particularly relevant to nursing, which values the perceptions of clients and families as well as the nurse's own perceptions as relevant elements of practice. Paterson and Zderad's (1976) humanistic nursing theory, based on experience as a "public health mental health psychiatric nurse" (p. 42), advocates a phenomenological approach to gaining new nursing knowledge. This viewpoint was pertinent since the researcher's experience also includes public health, mental health, and psychiatric nursing.

Study Design

The limitations of information already available were taken into consideration when designing the study. The studies reported in the literature (please see pages 11 to 14) followed more traditional methods, with the collection of information in the form of responses to preselected categories on questionnaires obtained by mail.

The conceptual leap from an experience to the choices of descriptive words on questionnaires in earlier studies was shortened in the present study by going directly to parents for a description in their own words. The researcher interviewed the subjects. In order to obtain as much information as feasible about certain domains of the experience of being a parent of a young adult with schizophrenia, the interviews were conducted in the relatively comfortable setting of parents' own homes, rather than the artificial context of an office setting.

The sample of parents for this study differed in several important respects from samples in studies reported earlier. Previous studies were surveys of members of family support groups, many of whom joined partly because they were upset with services provided. Subjects were a select population of family members with annual incomes averaging above $30,000. They tended to

be professional and business people. The subjects for the present study were parents who had a lower average income, who had attained a lower educational level, and who were not all members of an organized family support group.

Professionals were asked to identify young adult schizophrenic clients who met the study criteria and to obtain the young adult's informed consent to participate in the study. The researcher then contacted parents of those clients who had agreed to participate.

Guba (1978) suggests that the ideal naturalistic inquiry method encompasses a low degree of limitation on both the possible responses to research questions and the variables which precede the inquiry. An interview guide (Appendix B) was developed for this study to facilitate descriptions of the experience in parents' own words with minimal guidance from the researcher/interviewer.

"Qualitative data provide depth and detail" (Patton, 1980, p. 22) which are not available with quantitative data. The qualitative data obtained for this project included verbatim transcripts of interviews with parents, observations and impressions recorded by the researcher, and information from clinical records. Verbatim transcripts of the interviews constituted the bulk of the data collected and analyzed.

A process of content analysis was accomplished by examining the phenomena of interest contained in the verbatim transcripts. The categories for coding the verbatim transcripts of the interviews were drawn from the topics in the interview guide and from examination of the data as approximately the first third of the interviews were transcribed.

Setting

Naturalistic inquiry should be conducted in a natural setting. Since it was not possible in this research to be a participant observer in the actual experience over time of being a parent of a young adult with schizophrenia, the next best option was to ask parents to describe past events in a setting where some of the experience had taken place.

The setting for the study was at the homes of the subjects. Since parents were in their own home, had set the time for the interview, and had initial questions answered about the purpose in a telephone conversation with the researcher, a minimum amount of time was required to gain an attitude of trust at the beginning of the interview.

All of the interviews were conducted in the State of Utah, which has an estimated population of more than 1.6 million (Barber & Taylor, 1986). There are over 16,000

individuals in Utah who will have a schizophrenic disorder at some time in their life, if the generally accepted estimate of 1% of the total population is applied.

The homes were located in Utah communities which ranged in size from a sparcely-populated Indian reservation where only one other dwelling could be seen on the horizon to the largest city in the state, which is located in a valley with approximately half of the state's total population. Dwellings ranged from small frame houses on a sagebrush desert to homes in affluent areas of Wasatch Mountain foothills.

The researcher was invited into the home at the appointed time. In most cases, the interview was conducted in the living room or at a kitchen or dinette table. One interview was conducted in a vehicle outside the home. The identified young adult with schizophrenia participated either all or part of the time in five interviews. Other children and grandchildren of various ages were sometimes in the home but did not participate in the interviews.

Having other family members present at the time of the interview was somewhat of a distraction for parents at times, which would not have occurred in an office setting. However, the advantage of meeting in the home was that it was a natural setting. These types of

distractions occur at home and may add to stressful situations, giving the researcher a clearer picture of the experience for parents in their everyday family life.

Grandchildren were present in four of the homes during the interviews. Parents who were tending or raising grandchildren included one couple in their early 70s who were raising the child of their schizophrenic daughter, two sets of parents who were tending children of a sibling of the young adult schizophrenic on a temporary basis, and one set of parents who had several children and at least one baby grandchild living at home in addition to the young adult schizophrenic.

Some of the brief interactions with young adult schizophrenics who were in the home at the time of the interview are described later in this report. The conclusion from these interactions was that home visits with parents and the young adult schizophrenic could be very helpful. All of the young adults encountered in the home at the time of the interview seemed interested in participating, although some of them were allowed to participate and some were asked by their parents or by the researcher to leave during the interview.

Sample

Professional staff of mental health treatment systems in Utah assisted in the study by asking young

adult patients to participate. There was no shortage of patients in their case loads who met the study criteria: 18 to 35 years old, a diagnosis of a schizophrenic disorder, and at least one parent living in the area. Professionals obtained initial informed consent from identified patients and forwarded them to the researcher. Since professionals who risked a critical report were asked to select subjects, the possibility of a selection bias was addressed. Both positive and negative impressions of potential professional support were reported. The severity of illness among the young adults in the sample varied considerably.

The initial request for subjects went to the directors of various mental health programs in Utah, all of whom were known to the researcher. All of the directors who were approached submitted letters of support for the research proposal. A goal of numbers of subjects from each program, depending on the size, was set. The researcher contacted research directors and chronic care managers to ask for subjects as needed from each area.

One mental health program had a research committee which reviewed the proposal and made suggestions. One suggestion was that private and public providers of service be differentiated in the report. Another suggestion proved to be very helpful in gaining participation of

parents. The researcher had initially intended to have professionals ask parents directly to consent to the interview. The mental health program research committee required the development of a consent form for the young adult. The requested form was developed and the consequent involvement of the young adult proved to be useful. Most of them contacted their parents, which seemed to give the researcher an advantage in gaining the parents' consent for an interview. Having the young adults' consent also gave the the researcher permission to report information from their clinical records.

One initial concern in having to obtain consent from the young adult was that those with a diagnosis of schizophrenia, paranoid type, might not be represented in the sample, since suspiciousness is a common symptom of this disorder. This concern was unfounded, as at least 15 of the clients had this diagnosis, some of whom exhibited paranoid symptoms.

When it became obvious that more males than females were providing consent, the professionals who had agreed to help find subjects were specifically requested to contact female subjects. The final sample of young adults contained 16 males and 11 females.

An attempt was made to select a distribution of cases along a continuum of time since the date of diagnosis of the schizophrenic disorder. The number 30

was arbitrarily selected for the sample so that 3 groups of 10 each could be identified along a continuum of time since diagnosis.

A range of family socioeconomic status which was considerably lower than that of the studies of NAMI members reported earlier was sought. It was particularly important to gain information from less affluent people who did not belong to organized family support groups in order to gain information not previously available.

The criteria for the diagnosis which were developed for this study (please see Appendix B) were derived from the DSM III (APA, 1980). A psychiatrist who is knowledgeable about diagnosis of schizophrenia assisted in developing these criteria. In some cases, both outpatient and inpatient clinical records were examined along with descriptions of symptoms by parents in order to make a determination as to whether or not the young adult met the diagnostic criteria.

Thirty sets of parents of the identified young adult patients were sought as subjects for the study. A set of parents was defined as a father and mother seen together or a single parent seen alone. Stepfathers, stepmothers, and adoptive parents were included in the sample. Other relatives caring for the young adult were not included.

Professionals from various programs in different cities were asked to assist in the study. By selecting

various programs and both rural and urban communities for obtaining subjects, the researcher hoped to be able to describe experiences which were not related to a specific set of environmental and treatment program criteria in one community.

Instruments and Measures

The primary instrument for the study was the researcher herself. Her background and experience were helpful in gaining access to parents in order to obtain descriptions of their experience. Her preconceived bias regarding the neglect of parents by professionals presented a challenge.

"The strength of naturalistic inquiry is that the observer is sufficiently a part of the situation to be able to understand personally what is happening. The fact that the presence of the observer will change a situation is something that must be discussed and made clear" (Patton, 1980, p. 189). A perspective of the researcher's experience is included here.

The researcher's experience includes a bachelor's degree in nursing with psychiatric nursing experience in the 1950s. Nine years of subsequent experience were as a staff nurse on traditional veterans' hospital psychiatric units with a patient care routine not unlike that of the movie <u>One Flew Over the Cuckoo's Nest</u>. During these

years, families of patients were seldom seen by the researcher.

Two years of community health nursing experience provided the researcher with skills needed to make home visits and interact with a variety of people in their own homes to accomplish a specific purpose in health care. Regular home visits to individuals with a diagnosis of schizophrenia were a part of this experience. These clients were middle-aged adults and the families were seldom seen by the researcher.

Two years of graduate education in the mid-1960s emphasized intrapsychic and interpersonal dynamics of behavior in patient-centered and family-centered therapy. At that time, schizophrenia was seen by the researcher as a functional disease which originated in early childhood, primarily in interactions with parents.

From 1967 to the present, the researcher has had various experiences as part of an interdisciplinary mental health administrative staff. These experiences included assisting with the initiation and development of community mental health centers, reviewing state hospital programs in other states, coordinating changes in civil commitment laws, initiating a community support systems grant, and assisting with the development of family support groups as one of the community support systems, monitoring treatment systems for the chronically mentally

ill in community programs, and talking with many parents of young adults with schizophrenia at national and local meetings of the Alliance for the Mentally Ill. Some of this experience resulted in a conviction that professionals (including the researcher) had neglected and, in some cases, even mistreated (Appleton, 1974) parents of young adults with schizophrenia. There is abundant support for this point of view in the literature (Arieti, 1979; Beels & McFarlane, 1982; Berkowitz et al., 1984; Bernheim, Lewine, & Beale, 1982); Goldman, 1982; Hancock, 1981; Hatfield, 1978, 1979, 1981, 1982, 1983; Lamb & Oliphant, 1978; Pepper & Ryglewicz, 1984b; Raymond, Slaby, & Lieb, 1975; Shetler, 1982; Wasow, 1982; Wing, 1978; Wynne, 1981).

The researcher also has experience as a parent of young adults currently in their twenties. She has some idea of the stresses experienced by a family with "normal" young adults.

Interview Guide and Process

The approach to the subjects and the interview guide (Appendix B) were designed to introduce the researcher to parents as one who cared about what their experience had been and was interested in finding ways that professionals could be more helpful. The researcher was conscious of the need to gain information during the interview

without influencing the responses except for guidance toward the general topics to be discussed.

The interview guide was divided into six general areas: (1) early experiences with schizophrenia, including the meaning of the diagnostic label, (2) role of family members and friends, (3) role of professionals, (4) influence on family life, (5) neighborhood and community context, and (6) other pertinent information. The first five general areas dealt with domains of family life with schizophrenia in relation to stress and social support and the sixth was a series of questions designed to bring the interview to an end.

The beginning question for all interviews was "Would you describe how you learned that your son/daughter has a mental illness?" This question was designed to take parents back to their experience at the onset of the schizophrenic illness, then talk about the meaning of the experience and of the diagnostic label in the beginning and up to the time of the interview.

The experience with schizophrenia and the role of family members and friends was introduced by the question "Could you tell me about how other family members reacted to the disease?" Follow-up questions asked about what these individuals did or said and what was helpful or not helpful. The same questions were asked about close friends. These questions were designed so that helpful

and nonhelpful responses could be categorized in the data collection process to determine the extent and the dimensions of social support available to these parents.

The third domain of family life in relation to schizophrenia related to the role of professionals, beginning with the question, "Would you describe how you decided to consult a doctor or other professional person?" Helpful and nonhelpful descriptions of relationships with professionals and responses by professionals to them as parents were categorized to obtain information about the extent of social support provided by professionals as perceived by subjects.

The fourth domain was designed to gain information about the stressful experiences in everyday family life which resulted from the schizophrenia. These questions were often answered in the previous discussions, and seldom needed to be asked specifically.

The fifth domain of family life was the neighborhood and community context. Descriptions of supportive and nonsupportive responses of neighbors and of individuals representing community groups or agencies were elicited from subjects.

Concluding questions were designed to bring the discussion to a close, with an opportunity to report any other information the subjects would like to share about the experience, before asking whether they had anything

they would like to contribute in the way of advice to other parents or other ways in which professionals could be more helpful to parents.

Demographic Data and Rating Scales

In addition to the qualitative data of the interviews, quantitative data were collected on three forms, one each for the father and mother and one for both parents (Appendix B). This information included the present living arrangement for their son or daughter, number of other children, number of other children then living at home, sources of financial support for their young adult schizophrenic son or daughter, and an annual family income range. The race, age, and educational level attained was asked of each parent interviewed.

On the same forms, parents were asked to rate several factors. These included the level of involvement in a family support group, whether or not they had been involved in an educational series of classes about schizophrenia led by professionals, and the level of satisfaction with the present living arrangement of their son or daughter. Each parent was asked to comment on what they would prefer for a living arrangement, if they expressed any dissatisfaction with the present arrangement.

Information to support the diagnosis and the date of diagnosis was obtained from the clinical record and recorded on the form in Appendix B. The diagnostic criteria for a schizophrenic disorder for the purpose of this study included evidence of deteriorated social functioning as a result of the disease, a duration of the symptoms for at least 6 months, and at least one of the following:

(1) bizarre delusions,

(2) delusions-somatic, grandiose, religious, nihilistic, or other without persecutory or jealous content,

(3) persecutory or jealous delusions and hallucinations,

(4) auditory hallucinations, either with running commentary or two voices conversing,

(5) auditory hallucinations of more than two words not related to depression or elation. or

(6) illogical thinking, poverty of speech, and

(a) blunted, flat, or inappropriate affect,

(b) delusions or hallucinations, or

(c) catatonic or other grossly disoriented behavior (APA, 1980).

Informed Consent

Informed consent was obtained from the young adult schizophrenic patients. The informed consent form for young adults (Appendix A) includes a brief description of the study and its purpose, a statement that participation is entirely voluntary and whether or not they participate would not affect their treatment in any way, a statement about the confidential nature of the study, and an assurance that names or identifying information would not be used on any report. The form states that participation would involve permission for the nurse researcher to contact their parents and examine their clinical records and includes an offer to talk with the research nurse before making a decision.

An informed consent form for the parents appears in Appendix A. The form includes a brief description of the study and its purpose, a statement that participation is voluntary and that they could withdraw their participation or decline to answer any question at any time, and an assurance that whether or not they participated in the study in no way affected the treatment program for their son or daughter. The use of the audiorecorder to transcribe the interview is explained on the form along with an opportunity to decline its use. The confidential nature of the study is described along with an assurance that no names or identifying information would appear in

any report and that only the researcher would have access to the names of the subjects.

An acknowledgement that answering questions or talking about painful experiences might be difficult at times is included on the form. Also included is a statement that the information shared by parents might be used to help other parents in the future.

Data Collection and Analysis

One of the data collection tasks was to obtain a sample of at least 30 young adults who met the study criteria. The researcher was in frequent contact with key mental health personnel who were in a position to assist with sample selection. An effort was made to select young adults in each of the time-since-diagnosis categories as originally intended. The first category of newly diagnosed young people was the most difficult to fill.

As expected, the date of diagnosis was sometimes difficult to determine. Clinical records from outpatient and inpatient settings, verbatim transcript information from the parents, and inquiries of professionals who had treated the young adult in the past were utilized in establishing a date of diagnosis for the purpose of this research.

One of the early findings of the study was that some professionals were reluctant to diagnose schizophrenia and even more reluctant to inform parents of this diagnosis. In some cases, this phenomenon also made it difficult to determine in retrospect the date the diagnosis was (or could have been) made. In some cases, the diagnostic criteria for this study were utilized to determine in retrospect what the diagnosis could have been and the date the young adult apparently met the criteria was then used as the date of diagnosis.

Even though professionals were asked to submit names of individuals with a schizophrenic disorder, information from clinical records and from parents' descriptions of symptoms was examined to determine whether the young adult met the study criteria.

After receiving consent forms from the young adult, the researcher contacted parents by telephone in most cases. When the parents' home was a long distance from the researcher's office, clinical staff assisted in setting up appointments. For two interviews where the subjects spoke little or no English, an interpreter/clinician accompanied the researcher during the interview.

Process

The first question in the discussion guide (Appendix B) asked the parents how they first learned that their son or daughter had a mental illness. The question often resulted in a lengthy story about the development and course of the mental illness and the parents' experience with it. Many of the subsequent interview questions were addressed in this initial response before they were asked. There seemed to be no hesitation in reporting both good and bad experiences with professionals and other potentially supportive people.

The researcher attempted to follow-up the information already obtained with specific questions, such as, "Other than what you have already mentioned, could you describe how professionals were helpful or not helpful, or what they could have done or not done that would have been more helpful?" Usually, this question elicited more information about specific instances which could be interpreted as either helpful or not helpful. The question in the discussion guide about how their daily living had been affected was usually answered in the discussion and did not need to be asked specifically.

The subjects often mentioned the names of professionals whom the researcher knew. The researcher told the subjects that the names would be deleted from the transcripts and kept confidential. It was helpful for

the researcher to be familiar with these individuals in that she could often identify the discipline of the individual, since the subjects often did not know whether the individual was a social worker or a nurse, for example.

Since the researcher is also a clinician, she often felt inclined to take, but resisted, opportunities to offer information or suggestions to the subjects during the interview. A supportive stance was maintained by the researcher during the interview with the conscious aim of gaining their confidence so that they would share information. Several times, subjects were tearful when relating stressful experiences.

As the need for further information arose during the interview, the researcher made a mental note and addressed this need when it seemed appropriate after the taped interview had been concluded. Information was offered about the latest research on schizophrenia when it was requested. Information on the availability of family support groups and written information about books, newspaper articles, and newsletters was offered when it seemed appropriate.

The researcher was careful to avoid mentioning the term schizophrenia until one of the parents mentioned it, although the word did appear on each of the data sheets which the parents were asked to complete. Some of the

parents apparently did not know that a diagnosis of schizophrenia had been made.

Content Analysis

The process of content analysis began as soon as the first verbatim transcripts were available. The transcripts were read to get a sense of the content. A process of "cross-checking, triangulation, and re-cycling" (Guba, 1978, p. 13) was used to compare the categories which emerged from one piece of data to similar categories in other pieces of data.

During this process, "patterns" or "themes" emerged. For example, several of the first few subjects mentioned that they could more easily discuss schizophrenia with certain individuals than with most people. This pattern was "cross-checked" with information in other interview transcripts. This pattern was named "knowledgeable friend," until the pattern was found in an interview which concerned a relative. The pattern "knowledgeable person" was then identified to mean a potentially supportive individual who had knowledge about schizophrenia either from personal experience with a mental illness or from educational preparation in the field. This pattern then became a "corner" of the triangle which connected the concept from one interview to another. The process of re-cycling involved reading interviews or

parts of interviews over and over to identify and connect themes which were important to the research goals.

In the process of data analysis, the researcher had an advantage in that she had been present at all of the interviews, so that the data "came alive" in a sense that the written words without the experience would not have accomplished. Patterns or themes gradually emerged. Accounts of experiences with potentially-supportive people were separated into "helpful" and "not helpful" columns as the process of triangulation, cross-checking, and re-cycling from the data to the categories and back to the data continued.

The categories for coding the data were developed after about a third of the interviews had been completed. The categories (Appendix B) were then used as a guide in the data analysis and report.

Stressful experiences described by subjects and the subjects' perceptions of professional treatment programs, labels, and professional behaviors were coded according to two time frames: one chronological and the other time-since-diagnosis.

It was noted in the process of data analysis that professional treatment programs and the reported behaviors of professionals seemed to have changed over time. The perceived behaviors of professionals were then organized into time periods of before 1975, 1975 to 1980,

and after 1980. The perception of the degree of helpfulness of specific treatment programs, the described stressful experiences, and the perception of the label were also organized into these three time periods.

During the data collection process, it became obvious that most young adults who were selected and agreed to participate in the study had carried the diagnosis for more than 2 years. The decision was made to accomplish a perspective of the experience over time by analyzing the available data rather than continuing the attempt to identify three groups of subjects according to time-since-diagnosis as was originally planned.

Accordingly, stressful experiences and perceived behaviors of potentially supportive people as reported by each subject were organized into the original time-since-diagnosis categories, namely, less than 2 years since diagnosis, 2 to 6 years since diagnosis, and over 6 years since diagnosis. The types of treatment programs which were helpful or not helpful and the parent's perception of the label, schizophrenia, were also organized into the time-since-diagnosis categories for purposes of analysis.

The number of sets of parents in each time-since-diagnosis category were 4 who had been dealing with schizophrenia for less than 2 years, 7 who had been dealing with it from 2 to 6 years, and 16 who had a young adult suffering from schizophrenia for more than 6 years.

This constituted cumulative totals of all of the parents who had some experience in the early years, 23 sets of parents who had experience in both the first time frame and the middle years, and 16 who had experience with a young adult schizophrenic child in all 3 of the identified time periods.

The categories for data analysis included both helpful and nonhelpful perceptions of professional treatment programs, professional behaviors, labels (i.e., schizophrenia), and behaviors of other potentially supportive individuals and group members.

4. RESULTS AND DISCUSSION

Characteristics of Young Adults

A total of 32 young adults with a diagnosed schizophrenic disorder consented to participate in the study. Of this number, interviews were conducted with 27 sets of parents. The remaining selected sets of parents were not interviewed for reasons which will be discussed below. Demographic variables and other characteristics of the young adults whose parents were interviewed appear in Appendix C.

At the time of the study, the average age of the young adults was over 26 years and the range was 19 to 34. The average age of onset of schizophrenia was 19, with the range from 14 to 24. The young adults included 16 males and 11 females, with 1 of them Spanish American, 3 Native American, and the rest Anglo American. Diagnoses in addition to schizophrenia included substance abuse, depression, personality disorders, mental retardation, learning disabilities, and physical disorders.

At the time of the interview, 16 of the young adults were living at home with their parents and the rest were

residing in a residential treatment facility, alone or with friends, with a spouse, or in a nursing home.

The source of income reported for the young adults included supplemental security income (SSI), social security disability insurance (SSDI), public assistance, financial help from their parents, employment, savings, Medicaid (Title XIX), and Medicare (Title XVIII). Three of the young adults were employed in a sheltered work position and one was in a rehabilitation training program.

All of the young adults had been hospitalized at least once. Most of them had received inpatient treatment in a public as well as a private hospital. More than a third had been hospitalized in private hospitals only. All but two were being treated by a public mental health system at the time of the interview. None of the young adults were currently being treated by the same professional who originally diagnosed the disease. Only 2 of the young adults were currently married, 3 had been married, 3 were parents (only 1 of these currently had custody of the child), and 1 was a veteran of the Viet Nam war.

Professionals reported that 6 clients declined to consent to participate in the study. Reasons given included "don't want anyone to talk to my parents,"

"afraid of where it would go," and "don't want my parents bothered."

Five young adults participated all or part of the time in the interview. During three of the first few interviews, the young adult was allowed to participate. Two were females who seemed pleased to be asked to participate and were quiet and attentive. They offered few comments. An awkward situation arose when a father commented that his sister was often not helpful and the young adult seemed surprised to hear that about her aunt. That father also seemed hesitant to mention the word schizophrenia with his daughter present. One young adult who was present was obviously withdrawn and could be described as a typical "back ward" patient. Most of his conversation was limited to asking for a cigarette; however, he did show some of his drawings to the nurse researcher and offered a few comments, repeating what his mother had said, such as, "Pray, go to church." The other young adult was a male who commented that the interview offered an opportunity for the parents to really listen to him; he had to leave for an appointment, but hoped to be back before the interview concluded.

After these early interviews, the decision was made to arrange the interviews without the young adult present. Subsequently, 1 young adult participated part of the time. She had been asked to leave the room with

siblings by her parents after the purpose of the interview was explained. She came back in later and said, "I don't want you talking about me, I don't know why." The researcher turned off the tape to talk for awhile about her concerns. The two general interview questions left were then completed while she was present.

One conclusion reached from these young adults' desire to participate was that a home visit by a professional with parents and young adult could be helpful in providing and clarifying information, perceptions, and feelings among young adult, parents, and professional. Another conclusion was that young adults might be willing to participate in discussions led by professionals.

Characteristics of Parents

The subjects included 1 stepmother, 1 stepfather, 4 adoptive parents and the rest natural parents. In addition, 1 father and 1 stepfather were living in the home, but were at work at the time of the interviews. Another father was disabled and in the home at the time of the interview, but chose not to participate. Still another father was in a nursing home at the time of the interview and 1 stepfather was at home but chose not to be interviewed. Additional demographic variables for the parents are shown in Appendix C.

Of the 32 sets of parents contacted, 5 were not interviewed. Two refused in a telephone conversation, saying they just did not want to talk about it. Two were unavailable; both were widowed fathers who were out of the area and could not be rescheduled. Another was a family in which 2 members were willing to be interviewed (including the identified patient) and 2 members were reluctant to be interviewed. This family and 1 of the identified refusals said they would call back when they were "ready"; however, they did not call before completion of the study.

At least 15 families had a history of either a schizophrenic or an affective disorder, including 7 of the parents: 1 mother and 3 fathers with schizophrenia and 3 mothers who had been treated for depression or alcoholism. The average age reported for the subjects was over 53 for mothers and almost 56 for fathers, with respective age ranges of 34 to 70 and 44 to 72. Of the 46 total individual parents, 4 were Native American, 2 were Spanish American, and the rest Anglo American.

All but 3 of subjects indicated a religious preference. The sample was 70% LDS (Church of Jesus Christ of Latter Day Saints), which is comparable to the percentage in the state as a whole (Bureau of the Census, 1980). Of the 27 sets of parents interviewed, 19 indicated they were LDS. Positive support from their church was

mentioned by 6 of the LDS sets of parents, 2 had a negative experience, and 11 did not mention either a positive or negative experience. Of the others who indicated a religious preference, a Catholic, an Episcopalian, and a Pentecostal set of parents each reported a positive experience. A Protestant set of parents had a negative experience. The others did not mention a positive or negative experience with their church in relation to the young adult. The large LDS population may make Utah an atypical state in which to study the influence of churches on the problems of young adult schizophrenics and their parents.

The average family income was below that of respondents to the studies reported earlier. There were 20 family incomes reported below $30,000, with only 4 above (3 were not reported). Most of the parents were not involved in a family support group, with only 3 mothers reporting active involvement in a NAMI affiliate. The sample met the goal of a lower annual income level and a lower level of involvement in family support groups than that reported in previous studies.

Organization of Qualitative Data

The task of organizing and describing the most pertinent information from over 500 single-spaced, typed pages of verbatim transcripts was almost overwhelming.

No one interview typifies the experience of these parents. A clinical paper could be written on the data generated in any one of the 27 interviews. Trends and patterns related to the specific aims of the study provided the structure for organizing the qualitative data. In this presentation of the results of the study, a discussion is included in each section.

Descriptions of experiences with potentially supportive people are organized into the dimensions of social support identified earlier--size, content, timing, and intensity. Where deficits in social support for parents were identified, processes of professional support which might mediate stress and improve parents' effectiveness as caregivers are suggested.

Several issues in potential professional support are identified from the data and discussed, with suggestions for more effective processes of professional support. These issues included: (1) perceptions of professionals, (2) uncoordinated treatment systems, (3) lack of information, and (4) financial burden. The significance for nursing of the results of the study is addressed. Suggestions for more extensive professional support for parents by psychiatric mental health nurses and other professionals are made.

Dimensions of Social Support

Subjects described intensely stressful experiences with their schizophrenic young adult son or daughter. Especially when the young adult was living at home, parents described an almost continual state of some level of stress because of the unpredictable or unusual behaviors of the young adult. Extremely stressful experiences reported by subjects, all related to schizophrenia, included jail time for 11 young adults, 14 who attempted suicide at least once, 15 who destroyed property at least once, and 11 who had harmed other people. A discussion of the dimensions of social support available to the parents from professionals and other potentially supportive people identified deficits in effective social support networks in the experience of subjects.

Size

Potentially supportive people. Over half of the sample of parents described a decrease in the size of their social support network which was attributed to the young adult's schizophrenic disorder. In all but two of these cases, the young adult was living at home. The following are examples of the decrease in size of social support networks for parents who have a young adult schizophrenic living at home:

> [mother, case #24]: I have to give him pills four times a day....and as of right now he's

> doing pretty well...and I'm willing to sacrifice my time...but many times I do feel really tied down--that I'm not doing something for myself....They should have a place for young people [not a nursing home]....He was unhappy in a nursing home.
>
> [mother, case #26]: I don't have a lot of close friends...friends in the church and that --I don't tell them. I just don't talk about it. I don't know if they know or don't know....I'm actually very religious, but I don't go to church because of [embarrassing behavior of husband, also schizophrenic].
>
> [mother, case #13]: I feel guilty leaving him even to go out to dinner. We never go on vacations, except when he can come with us.
>
> [mother, case #4]: I kind of withdrew from people....I had one girl friend that was very supportive. She reacted as a sounding board for me when I felt angry and wanted to curse at [young adult]....But most people if you shared it with them and they liked me they became negative toward [her]....So rather than hear their negativeness...I avoided people.

Professionals should be aware that social support available to parents may be restricted in some way and be insufficient to mediate stress, especially when the young adult client is living at home. Parents can suffer loss of self-esteem and loss of freedom with this burden of care. When appropriate, professionals should encourage parents to attend to their own needs for socialization and personal freedom.

Efforts by both professionals and parents to facilitate residential alternatives and social and vocational rehabilitation for young adults could move them toward more independence and free parents to seek a

more satisfying social life for themselves. Of 18 individual parents indicating a preferred living arrangement for their young adult on the questionnaire, 6 mothers and 3 fathers wanted a more structured residential alternative and 6 mothers and 3 fathers wanted a more independent living arrangement.

Family support groups. Although NAMI affiliates were available nearby for all but three sets of subjects, 15 mothers and 15 fathers had never been involved in a family support group. Some or moderate involvement was reported by 8 mothers and 4 fathers, and only 3 mothers reported active involvement in their local NAMI affiliate.

Three sets of parents said that they appreciated the information on the support groups provided by the researcher after the interview and might attend in the future. Other parents said that they did not feel like talking about their problems in front of a group or were too busy to attend. One mother had attended meetings and found it "depressing." She noted that they had never felt ostracism and that their family and friends were supportive.

No specific issues were identified from the data to differentiate parents who do belong to family support groups from those who do not. Two mothers who had been dealing with schizophrenia for more than 9 years had

different views on the family support group's usefulness to themselves:

> [mother, case #13]: But I really haven't gone to those....if it was...back where we were having all the problems, and everything, then I probably would have knocked myself out to get to that.

> [mother, case #7]: And these meetings that I go to have helped me immensely to handle problems. Before, when [young adult] was doing these weird things, I would just go completely to pieces. And now I've been able ...to not fall apart and become panicked.

Professionals should be alert for opportunities to suggest family support group involvement to parents, realizing that some parents would take advantage of the opportunity to join, some parents might not be inclined to join groups, and some might be encouraged to attend an educational session where they did not have to share their problems.

Professionals might become knowledgeable themselves about local family support groups, offer to provide consultation to them, and be aware that criticism about professional practice may be forthcoming. Professionals could be alert for opportunities to clarify misinformation and correct problems whenever feasible. There should be open communication where appropriate between the treatment system and the family support group.

Family support groups might increase the size of social support networks for parents by identifying

knowledgeable persons to turn to in times of trouble. The groups could also be a source of a rise in self-esteem for some parents as they learn that others share the same difficulties. Group meetings could be helpful by providing information about schizophrenia and about behavior management techniques which have worked for others.

Content

The content of social support for subjects was described in terms of attitude and culture. An apparent attitude change on the part of professionals who provide family intervention was noted over the last fifteen years. A "cultural gap" which the data indicated exists between parents and mental health treatment systems is addressed below.

Attitude. Both supportive and nonsupportive attitudes of other people, including professionals, were reported by subjects. Approximately one third of the subjects reported a relationship with a knowledgeable person with whom they could discuss their problems and find a supportive attitude, while relationships with other people tended to be more superficial in terms of avoiding the subject of schizophrenia. The "knowledge" possessed by the supportive other person was either by way of experience with their own or a family member's

mental illness or by way of education and experience with mental illness in their line of work. Examples of support from a knowledgeable person were:

> [mother, case #7]: I have a very close friend that's real supportive...'cause her son's killed himself. And every time [young adult] tries suicide or goes off the deep end so to speak, she's right there to help me.
>
> [father, case #6]: We have one or two close friends around here. In fact, our neighbor... has been the most understanding of any person. Because she kind of had a problem with depression.
>
> [father, case #23]: When the Bishop [lay church leader, also an MD] decided we should get her some help then we got it....helped with the medical bills, too, they've been very good in our ward.

Parents reported supportive responses on the part of relatives, friends, professionals, church officials, and law enforcement officers, including the following examples:

> [mother, case #18]: Her brother is so good to her. He pampers her and babies her along and takes her to shows....he's probably the only person in the world she really loves.
>
> [father, case #13]: [young adult left home; had been talking about going to another state] I guess it was the next day we got a phone call from...the sheriff down there...he'd come in looking for a place to sleep...and wouldn't give him his name...he had a Bible with his name....So he finally give him our phone number....But [sheriff] said "Don't worry about him, I'll find him a place to sleep tonight. He was down here looking for a job, and I'll call you back and let you know how things work out." So we thought that was pretty nice of him....and so the next day he called and said that there was a family...that ...needed some

help up there, so he was gonna go up there and work. So he did, he was there about six weeks.

[mother, case #7]: I called the nurse and she says, "He's been pacing the floor...we won't let him be miserable tonight Mrs....try not to worry." So the kindnesses. This means so much. Because we're here and we're wondering how serious it is and we don't know.

[mother, case #10]: The doctor that called me the other night is the first person that even acknowledged me....I was able to ask him questions--he took time. And I found out there is a possibility...[young adult] can function and probably live a pretty good life....I appreciated that. That man's sharp. He give me hope.

The attitude of professionals and other people toward the subjects was not supportive in the following examples:

[mother, case #12]: And I don't need their pity. I need their help and understanding and my son needs it. I don't want their pity. That makes me angry, when that's all I get.

[mother, case #13]: Then we took him in to the psychiatrist...every week....And I think that made him <u>worse</u>....It was <u>terrible</u>. I'd go in with him, and every time we went in, they had someone different there to talk to him, and <u>he'd just go through the same thing</u>!...I felt like <u>I</u> was...gonna have a nervous breakdown!... [father]: It looked to me like they were... training their interns or whatever you call 'em.

[mother, case #5]: My mother-in-law was not helpful at all. In fact she made it very difficult because she kept expressing her belief that [young adult] <u>could</u> control his behavior. She saw some things on television or in the paper about schizophrenia and she is much more understanding now.

> [father, case # 3]: But see, they wouldn't tell me nothin'. Yet they wanted us to be the financial support of the thing.
>
> [mother, case #7]: I tried to put a personal call through to the doctor to find out exactly how [young adult] was trying to kill himself and what they thought of it. And he never returned my call.

Parents may suffer loss of self-esteem and loss of a sense of control because of stressful situations. Professionals might alleviate some of this distress by treating parents with respect, providing them needed information about the treatment process, and recognizing that they may have a contribution to make as a caregiver, in addition to financial support.

A trend away from family therapy based on theories of a direct parental cause and toward supportive family interventions was noted in the data over time periods since before 1975 (Table 1). This finding is supported by only a few cases (8 of 27). Of 4 subjects reporting family therapy which blamed the parents, two received therapy before 1975, two during the period from 1975 to

Table 1

Attitudes in Family Intervention

	<1975	1975-80	>1980
Blaming	2	2	0
Supportive	1	1	2

1980, and none since 1980. All four of the subjects reported very distressing experiences with this type of family therapy. Examples were:

> [mother, case #18]: The whole family went into therapy. And that was one of the most traumatic things I've ever done in my life! And finally one day [therapist] said, "Oh, my God, how does it feel to be perfect?" You know--we were tryin' to be honest and tell what our reactions were to these situations. And we weren't a family that argued and quarreled; we get along....I guess she wasn't getting the responses that she expected. [father]: [joined interview after exchange above] She [therapist] absolutely tried to put all the blame on the family! [mother]: [laughed] except I felt like it was all <u>my</u> fault!

> [mother, case #4]: And that was a big farce. I really haven't felt comfortable in group therapy with her since....And if I went there it seemed like every week when it was time to go [young adult] would do something the day before that made me so distraught I couldn't deal with life itself....And if I'm unhappy I jabber a lot or I'm tearful. And they would always say, "Well, now it looks like mother's going to cry today to get the attention of her family."...every one of us went....my husband and me and the other six kids....At that time, the center focused all the blame on the family. ...basically the mother....The good thing that came out of it was I quit drinking.

Helpful family interventions were reported by one set of parents in the time period before 1975, one in the time period 1975 to 1980, and two since 1980. Professionals in each of these cases were reported to be supportive, with practical suggestions for improved family functioning. Examples were:

> [mother, case #22] they brought us in to the [children's hospital] as a family and helped us by setting up a household schedule. That was helpful.
>
> [mother, case #24] This one therapist [social worker]. He really did a lot, not only for [young adult] but for the whole family....We went every week for a whole year....he'd have us all in this room and then we'd have games, we'd talk, and things.

Given the problems parents described in dealing with every-day situations in the life of a family with a schizophrenic young person, the data indicated that a supportive type of intervention with the family might reduce stress and increase self-esteem for parents and help them gain control in the family. Supportive family interventions could also reduce unnecessary stress caused by unclear communications and lack of knowledge about the nature of schizophrenia and about the medications.

However, most professionals may not have the education and skill to provide effective interventions with families of schizophrenics. Hatfield (1983) feels that professionals should use an educational model rather than a medical model with families. She found a considerable difference in goals for family therapy between families and professionals.

Terkelsen (1983) pointed out the negative effects of family therapy on families of schizophrenics. He found through his own experience that some of the conclusions made by professionals that all families of schizophrenics

are dysfunctional may be due to two iatrogenic causes: "(a) failure to absolve the family of initial causal responsibility, and (b) failure to inform the family about the nature of the illness" (p. 191).

Psychoeducational models of family support and home visits by community health nurses have been discussed as effective interventions with families of schizophrenics. Professional educators might consider teaching these approaches and others to graduate students. Types of supportive approaches for parents could also be included in continuing education programs.

Culture. Information on one ethnic minority, a Native American culture, was obtained from 3 of the sets of parents. Attitudes arising from the cultural context of families and neighborhoods were described by subjects. The cultural context of mental health treatment systems, so familiar to professionals, was foreign to parents in many instances. Examples of various cultural contexts of schizophrenia are provided.

The Native American subjects sought help from both "traditional medicine" and "White Man's medicine." Two of the families lived on a reservation and the other lived in an Anglo community. This latter family traveled some 400 miles to get help for their young adult from medicine men, one of whom was the young adult's maternal grandfather. Experiences were related:

> [mother, case #11]: She wouldn't take that pills, she said she didn't want it....then we left from here to go back down to....[another state]. [father]: White Man's doctor don't help, we might's well try our own medicine men. See if they'd help us. [On the reservation in another state] they work together like that! [gestures]...Medicine men and the White People, a doctor--they work together.
>
> [interpreter for mother, case #20]: She said that when he first came back [to the reservation] and when she found out about this problem, he was so bad that she took him to some medicine men and that's how he kinda' got better....She's saying that there's some fluid, I guess in his brain or somewhere, that she thinks is causing the problem.

None of the Native American subjects knew the label for their young adult's problem as schizophrenia. Two of the subjects spoke almost no English, and there is no word for schizophrenia in their native language. The other set of parents knew that their young adult had a mental illness, but understood from both Anglo and Native American experts that the main problem was drug abuse.

Professionals should be aware of health care practices in other cultures. They may need to coordinate care and treatment where possible with providers of other cultures.

About half of the subjects reported supportive environments of family, friends, church, or neighborhood. Examples of reports about supportive families and friends were:

> [mother, case #18]: We have life-long friends! ...They always inquire about her and when they

see her why, they love her and make her feel special. And well, they're just caring people. We've never had any ostracism.

[mother, case #16]: The boys [young adult's siblings] stuck with us....and they all were here when it first happened. You know, it was a shock. They all took turns. One of them flew over from Utah be be with her...other lived in California so he was the first one to get to the hospital to see her.

Examples of a cultural context which were not supportive to parents were:

[mother, case #12]: I think that we've had more hindrance than help....I think that a lot of families--this is the taboo. I mean, this is something that...you're supposed to hide it. You're not supposed to even talk about it.... [With some people], I can't use that word [schizophrenia]....Because then I have to explain it....You know, "It's schizophrenic, oh my God." And they get this dreadful look and they don't want their kids around your kid because they're afraid of him...."Hey, I don't want my kids to catch...craziness."

[father, case #23]: I'm sure...if I'd been in large city I would have had a lot better help....I feel that unless you're a strong LDS person in this town you're not going to get nothing....They LDS people would have come to my house in [large city]. 'Cause I lived there and I know.

[mother, case #8]: Well, his brother...just couldn't face the reality....and he was ashamed. And I could tell when he brought his friends around...he just wished he'd get lost.

Professionals need to have some awareness of the content of social support in the cultural context of parents' environment. Where appropriate, parents can be encouraged to take advantage of social support within their own culture to maintain or improve self-esteem.

Where there are deficits in social support, professional support might be able to alter the disparity by providing a continual relationship with a professional who is available in times of crisis, offers individual therapy if desired, and endeavors to impart a sense of esteem and recognition of the parent as a caregiver.

The cultural context of a hospital or other treatment system was somewhat foreign to most of the subjects. Parents seemed to lack knowledge about how to gain access to information, especially in a hospital setting. An example of this lack of knowledge of the culture of a treatment system was:

> [mother, case #3]: We talked to [the psychiatrist] once. And we could never talk to him again--there was no communication with the doctors, the psychologist, yes, and the social worker....But the doctors...I don't know why they don't want to talk to you. [father]: He'd surely diagnosed her and could a at least talked to us about her a little bit.
>
> [mother, case #10]: And this [psychiatrist] ...he just acted like I wasn't even there. And I thought, "Well, maybe this is the way it's supposed to be, I don't know."
>
> [father, case #7]: One time--I was real mad about this and so was my wife--[young adult] was having a problem here at the house. And right in the middle of the night...we hauled him into the [public] hospital, it was foggy and everything else, and we got up there and the doctor on duty wouldn't do a darn thing for him. Told me to take him home and let him come back in the morning.

The majority of subjects, 21 of them, mentioned that they would like to talk to psychiatrists more, but that

they were generally inaccessible. Parents wanted information about their young adult's condition and about medications. Parents appreciated psychiatrists and others who treated them with respect and kindness.

When the young adult was on an inpatient unit, social workers were the primary professional to talk to parents, explain the progress of the young adult, and assist with discharge plans. Parents were usually appreciative of the attention given them by social workers on an inpatient unit. Social workers sometimes provided them with substantive information on the disease and the medications. The subjects seldom remembered receiving support from psychiatric mental health nurses on an inpatient unit, although they usually mentioned that nurses were apparently supportive of their son or daughter.

Parents were less-informed about the professional discipline of mental health personnel in the community than in the hospital. Parents sometimes identified a professional by a discipline that was not accurate; for example, a social worker might be called a psychiatrist or a psychiatric mental health nurse might be called a social worker. The discipline, except for physicians in most cases, was not important to parents; the professional's behavior as an individual was important.

An example of how another agency helped bridge the cultural gap by helping the parents learn about a public hospital environment was:

> [mother, case #17]: He was kind of doing things in the [juvenile] court...and the woman that was in charge of him--she put it to him that they thought it was a good thing if he went down at the [public] hospital. So, at first I got really uptight because I thought it was just for the really crazy people....So she really give me a good justice by telling me--describing it before we got down there. And then we went through the whole facility and I felt really comfortable. It was really a good thing to do.

Professionals may be able to orient parents to the treatment system, with information about how to contact the psychiatrist, how other professionals can help, any rules and regulations which might affect parents, and the nature of the treatment program.

Timing

Childhood years. Parents' description of the childhood years of their young adult with schizophrenia varied widely. Examples are: "18 years--no problem," "beautiful child," "we had trouble from the time she was a baby," "slow learner," "could never learn to read," "she was getting straight A's," "he was a problem child," "he was doing so well in college," and "he was a loner."

The wide variation in reported childhood experience in this sample of families does not support a theory that faulty parenting is the specific cause of the development

of schizophrenia in later years. While professional intervention might have been helpful in alleviating other problems, it is not likely that prevention of schizophrenia could have been accomplished with early intervention in the families of the subjects.

A family history of mental illness in 15 of the families was reported. Two of the subjects reported that they were very concerned about a female young adult becoming pregnant, partly for burden of care reasons and partly because of the genetic nature of the disease. They had inquired of physicians about sterilization, and were quite concerned that this had not occurred. Genetic counseling could be useful in planning for future generations and might be facilitated by professionals for young adults and family members when requested.

Onset. Because of the nature of the diagnosis of schizophrenia as a long term disease with prodromal or acute symptoms of at least 6 months duration and because the initial symptoms are difficult to differentiate from other conditions, a period of 2 years is described here as the onset phase. The DSM III (APA, 1980) makes a distinction at the 2-year point in the course of the schizophrenia: more than 6 months but less than 2 years is either "subchronic" or "subchronic with acute exacerbation" and more than 2 years is either "chronic" or "chronic with acute exacerbation."

The onset of symptoms first noticed by subjects was described by parents as a personality change for 10 young adults, behavior best described as "weird" for 2, violent behavior for 3, and frightening delusions for 8. The other 4 young adults had onsets over a longer period of time which were not specifically described, onsets which were confused with other conditions, or onsets which were not observed by parents because the young adult was away from home at the time.

Parents described enormous personal stress during the onset of schizophrenia. Examples were:

> [father, case #23]: Her eating habits... changed and her personality started changing ....right at the time of...my wife's death. She had a job at that time. And after two or three weeks, she was not able to work.
>
> [Mother, case #18]: So many times I'd find her just coming out of the closet...and I'd think "Well, for <u>weird</u>... why is she doing that?"...[then, later] she was just getting worse and worse and worse, in spite of having medication. And I got to where I would be driving down the street and I would go through a red light. You know, I was under so much pressure to try and cope with what was happening, cause, you know, you couldn't leave her alone for a minute.
>
> [mother, case #15]: All of a sudden, she looked out the door and she said "Oh! Don't you say such a thing. How could you be so cruel!" and I said "[young adult], who are you talking to?" and she said "...just called" and said all these things, and I said "Honey, I've been sitting right here and the phone didn't ring." and she said "Well, she didn't call, she stood right out there on the corner of the lawn and yelled." And then I <u>knew</u> something was terribly wrong. A little while later, she came

> up and said "Mom, it's all right. I've taken care of it. It's dead."...I found out she had taken a whole bottle of Tylenol...and what she was thinking that there was something inside of her and by taking all those pills, she had killed it....It was the most terrifying thing I think I've ever gone through.
>
> [father, case #25]: [young adult] was down at ...College...he told us that that quarter he was very depressed and didn't go to class...and hardly ever got out of bed....That was when it really hit me.
>
> [mother, case #11]: She was jus' acts weird and she was cryin' and cryin' and I said "What's wrong?" She says "all these students they laugh at me, they talk about me--the way I dress".... And then I brought her home....So she went downstairs...I thought she was asleep ....Then I finally knock on the door....Then she was jus' standing in the middle of the floor....and she wrote on the wall <u>all over</u> ...and said "Jesus is gonna take me away."

Psychosocial stressors which were reported to have occurred near the time of onset of the schizophrenic disorder included death of a parent, divorce of parents, death of a grandparent, church mission, marriage, divorce, college, and the birth of a child. Sometimes the beginning symptoms of schizophrenia were seen as a transient reaction to the stressor:

> [mother, case #15]: It was just before her marriage and the first psychiatrist she seen thought that it was just like "normal" people reacting to marriage...because it was just before she got married that she started hallucinating. The first psychiatrist thought it was paranoia.
>
> [mother, case #16]: That would be her first attack. They called it a postpartum depression. She just come unglued and come up and

> start sayin', "the snakes are gettin' me," and you know she was berserk...it was scary.

Professionals need to be alert to symptoms which may be due to stress, or may be symptoms of schizophrenia which are aggravated by stress. They could help parents deal with the possibilities of various potential diagnoses. Wolfer and Visintainer (1979) noted that anticipatory guidance by pediatric nurses which prepared a young child both cognitively and psychologically for noxious procedures in tonsilectomies resulted in improved outcome for both parents and child on measures such as pulse rate, time of voiding, and parental satisfaction with treatment. Similarly, professionals might consider helping parents understand what behaviors might be expected with the disease or medications and suggest ways to manage behaviors and contact professional help.

Anticipatory guidance might be helpful for parents at the time of onset of symptoms which may be indicative of schizophrenia. Respondents in this study frequently reported not knowing where to go for help. One parent stated that she would advise parents to seek treatment from the public rather than the private sector:

> [mother, case #13]: I think it would be nice if there were just some place that they <u>Knew</u> they could go. Now, see, I would know now.... maybe psychiatrists help some people, but I didn't feel like there was any help there. Now, if we had the problem again, that isn't where I would go--to a psychiatrist. I would go to the mental health center.

Professionals need to be aware of the distress suffered by parents during the onset of symptoms. Unpredictable, terrifying behaviors and uncertainty about the cause or the long term effects can be devastating to parents. Parents could benefit from a relationship with a professional who will listen to their concerns, treat them with respect, and recognize the burden of care of this young adult with the baffling behaviors. Parents are likely to suffer loss of esteem, loss of a feeling of control as parents, and a loss of independence with a burden of care that is overwhelming.

Parents often do not know where to turn for help. A caring, competent professional could alleviate some of this distress at the onset of schizophrenia. A continual relationship established with a professional as near the onset as feasible could be most helpful at this stressful time period.

Middle years. The experiences described by parents during the period from 2 to 6 years from the diagnosis of schizophrenia generally included both hope for improvement with remissions of the symptoms and frightening reoccurrences of behaviors which often necessitated hospitalization. Different professionals and different treatment systems were tried. None of the parents interviewed reported that the same professional or even

the same treatment program had provided service to their young adult over the period since the first symptoms of the schizophrenic disorder.

Later years. Many of the worst behavioral outbursts no longer occurred after 6 years. The stressful experiences for subjects were described as deepened and prolonged, rather than sudden and frightening. Parents expressed some relief that their son or daughter was improved. Intense sadness or grief about the "loss" of a once promising child and worry about what would happen to their child in the future was expressed. Thirteen of the young adults who had been living away from home at one time were now back living with their parents. Subjects expressed sadness and distress at having a young person come back home to live rather than being an independent adult. Examples of experiences during the later years were:

> [father, case #6]: And the time we brought him home from there [public hospital], because he didn't have any place else to go, we brought him home here....And we looked at each other and we said "We can't go through this because it's devastating to us to have him...here."
>
> [mother, case #7]: But we can see where [young adult] right now has made a big improvement as long as he stays on his medication. But the minute he goes off his medication--now about 6 or 8 weeks ago he tried to kill himself again. [father]: You know it's bad on [wife] and I too, because when most of this stuff happens, it happens at night. We're getting to the point that we can't even see driving at night. [mother]: All I can see is hopelessness. No

> cure. I can't see any happiness....It's just a terrible feeling for a mother to realize that there's nothing in days ahead for him. What worries [husband] and I is when we're gone, what's gonna happen to him? Because he has no friends....He's got his brothers and sisters, but they've got their own lives to lead.

Parents who have been dealing with schizophrenia for many years are usually somewhat familiar with treatment systems. They continue to need professional support to deal with less frequent crises and to help them move their young adult to as independent a life as feasible. Social and vocational rehabilitation and residential alternatives should be facilitated whenever feasible so that parents might regain control over their own lives and have some sense of a future for their young adult.

Intensity

High levels of expressed emotion (EE) in families has been discussed as a precipitant of exacerbation and rehospitalization for schizophrenics. In the judgment of the researcher, 12 of the subjects in this study were demonstrating high levels of emotional overinvolvement with their young adult. No objective measure was used. In all but 1 of those cases, the young adult was living at home. The following examples from the study indicate that intense emotional overinvolvement is also extremely stressful for parents:

> [mother, case #19]: Twice I had to have the police here, because she'd get so damn violent

that she broke my kitchen door window.... Apparently, when she done this, [the therapists] wouldn't let her have a thing to do with me, they said they didn't want her calling out here or me callin' her....well, in the meantime, therapist called me and...said to me "Well, Mrs....can't you be a little more kind?" I was kind to [her], but I'm so damn scared of her!...because she did get mad one night and she hit me in the face and broke my glasses, and oh, I had a gash here in my face...and I know at the time that she was upset herself.

[father, case #14]: We were just in a high level stress. I was about ready to have a nervous breakdown. I couldn't control him.... he'd come through here and turn on every light, open every cupboard, every door. He was turning the heat on and off and then he'd bang on the wall to try and get me to come out so he could...fight with me....So, we called the police [to] pick him up....And in the emergency room [young adult said] "Sure, you bet, I'll do that."...And so I got the feeling this guy doesn't even know what we're going through here....When he gets off of his medication he doesn't sleep....I came out one evening and said..."I've got to sleep. I've got to go to work tomorrow morning. Please go to bed." And, oh boy--just that kind of an approach and he just exploded.

[mother, case #10]: Our life is just--sometimes I don't know whether I know what reality is anymore....Of course, for him it's worse than for me. I find myself, I get angry at him, because I feel like he's not trying hard enough. And I know he's trying with everything he has....And sometimes I wonder if I'm still trying to shove it in the back, pretend it doesn't exist. Because it's sometimes really hard. It does exist and it's real and it's with us 24 hours a day.

[father, case #2]: I'm not good for her, I know. I just get too upset with her. She was living in the [residential facility] for awhile, then she moved to a dump, then her mother took her back. I wouldn't have. I've just about had it with two schizophrenics in the family [his wife and daughter].

> [mother, case #4]: We weren't even told a whole lot when she was in the [public] hospital these last 3 1/2 years. In fact I was turned away from there more often than not and was told that I was stressful for [young adult] to be around. And it would upset me so bad. I would cry and I would cry. Because out of the whole family I was the one that would never lose hope....My husband [at work at the time of the interview] said, "If this is the life she chooses there's nothing else we can do. We've fought it for enough years." She had gotten to the point where they [the family] just didn't want to have a thing to do with her...she could just in seconds turn the household upside down.

Professionals should be aware of the level of emotional overinvolvement of parents with the young adult and that there may be other emotionally-charged problems in their environment. The elements of professional support, including a continual relationship, an esteem for and recognition of parents as a care provider, and a process of informing parents about the disease, medications, and behavior management might be helpful in reducing the level of EE. Other methods to reduce high levels of EE should be considered, including individual or family therapy, if desired, and facilitating social and vocational rehabilitation and supported or supervised living alternatives away from the parents' home.

Issues in Potential Professional Support

Perception of Professionals

When asked how professionals had been helpful or not helpful, most subjects responded that professionals had

been helpful to their young adult. Clearly, these parents felt that the most important thing that professionals could do to help parents was to help their young adult child.

Subjects had individual perceptions of whether a specific professional was or was not helpful in providing information and support to themselves as parents. Sometimes, a husband and wife would disagree on how helpful the individual was. The following are examples of parents' perceptions of professionals:

> [father, case #15]: When we talked with Dr. [psychiatrist] that was...good--because really, I think he opened our eyes to a lot of things we didn't understand....[mother]: Dr. [same psychiatrist] didn't for me, <u>at all</u>. Dr.... <u>left me cold</u>....[father]: Well, the way he opened my eyes was that on the medications and things that we had been giving her that the other doctors had <u>not</u> told me--specifically what to look for....[mother]: But after he talked to us, he never did anything that he said he was going to do.

> [father, case #1]: Now, one young doctor [actually a social worker] down at the [public] hospital....I think he was the most informative of any that we have talked to, and he told us about everything--what to expect and.... [mother]: I have the wrong opinion of him, then; to me...some of the statements he made, he was very young and he sounded to me like he was reading out of a textbook.

The most appreciated aspects of professional support for parents seemed to be that the professional treated them with respect and kindness, provided them with reassurance that their young adult was being treated

adequately, provided them with information on their young adult's progress, and were available when needed, even though substantive information on schizophrenia and medications was not given to the parents. For example:

> [mother, case #1]: Oh, what a darling man [psychiatrist at public hospital] he was! We just fell in love with him; he was the sweetest, kindest man that we ever met, and caring. And he was marvelous with her and with us....He was very reassuring, and if there was anything derogatory to say, he would say it...you want to be told, you don't want things smoothed over all the time....No, no, we weren't told too much [about schizophrenia or about medications] down there....We just thought he was kind.

Professionals need to be cognizant of the impression they might be making on the parent which may interfere with parents' ability to process information. Processing of information by repeating it in a different way or by helping the parents to ask pertinent questions and discuss their understanding of it in relation to their young adult might be helpful.

Uncoordinated Treatment Systems

Almost all of the subjects reported experiences with what appeared to them to be uncoordinated treatment systems. Examples of parents experiences with what they perceived as problems follow:

> [mother, case #15]: This was when she stabbed herself....And then she got all completely off her medication and she was actin' so normal, then they put her down in the psychiatric ward and she kinda' come unglued...they [private hospital] didn't even know what the mental

> health had been doing for her. And what they did for her up there--they never even reported to the mental health.
>
> [father, case #6]: [mental health center psychiatrist] said, "Well, I think he's on too much medication."...They'd just spent 8 months up there [public hospital] getting it to this point....I bit my tongue right there and said, "Oh, God, don't upset it."
>
> [mother, case #8]: They put him on 3 years probation...with the stipulation that he would receive counseling through...County Mental Health, because that's where he was living at the time....And so he got a social worker... that was just excellent with him. But...he was living with us [in another county]....And I said "Please don't drop him until he gets a little more stable."...Well...the funds were restricted, and they had to drop him. So then it took...about 2 to 3 months to pick him up on ...County rolls....He was [on medication] but of course, in between he didn't get it.
>
> [father, case #2]: She was in and out of hospitals...all big state hospitals. And when she'd go back in, they'd start all over.... There has to have been something written on her, so that they could continue rather than having to start over.

Professionals might explain to patients and parents why they need some information first hand, rather than relying on previous reports. However, professionals might consider parents a potential resource for information on former treatment and take advantage of the continuity of care which a phone call to another professional could facilitate. Professionals should gather collateral information from parents and from other treatment programs, utilizing the information whenever feasible to proceed with treatment.

In order for professional support for parents to occur, a continual relationship should be established with parents whenever feasible, preferably by one professional, such as a primary therapist or case manager. Parents need to have a professional who is available for information and support over the long period of time that the young adult is in treatment. A primary therapist for the young adult was identified by 13 sets of parents. Two of the primary therapists were mentioned as having especially good relationships with parents, providing information and support readily:

> [father, case #16]: And any time we wanted something, we'd call [primary therapist, a B.S. mental health worker] and [she] would tell us. No argument.
>
> [mother, case #1]: She [primary therapist, psychiatric mental health nurse] has told us that...she felt that we were some of the most supportive parents that she had ever met; that she had met parents, that would say, "Well, OK, they're on their own; just don't bother us about it."

Subjects described both helpful and nonhelpful behaviors by other identified primary therapists. Examples were:

> [mother, case #2]: The one [primary therapist, psychologist] she's seeing now; I wish that it were easier to talk to him...if you call him you can't get him, and when she needs help, she needs it whether she agrees on it or not....he says to have her call and she won't always call.

> [father, case #23]: [mental health center] put her on medication and I just worried about it...thought it was too strong and a...the follow-up [by a nurse]...wasn't too good....And I couldn't see anything changing....[he took her out of treatment] If they would have explained the medication better--[maybe I would have continued her in treatment]

Parents may have strong feelings about the treatment being provided, even if they do not come forward to express them. The data show that professionals could use parents as a resource of information about treatment and care previously provided and about the response to current care and treatment. Professionals often need to obtain information from other treatment agencies in order to develop an effective plan of care. The data indicate that professionals should keep parents informed and involved in the treatment plan, if feasible, and that professionals should acknowledge the parents' role in continuity of care. Parents who are in the role of primary caregiver need to have information about the treatment and the medications being provided and any change in therapists which may be made.

Lack of Information

Confidentiality versus a need to know. An issue identified from the data and from the researcher's own experience was that professionals sometimes consider all information about the patient as confidential, when some information should be shared with persons who need to

know for the purpose of continuity of care. Some of the subjects had some understanding of the confidential nature of the young adult's communication with a therapist. Examples were:

> [mother, case # 10]: I don't feel like it'd be fair for me to talk about the professionals, because I haven't, like I said, the doctor that called me the other night is the first person that even acknowledged me. And [young adult] is 21, I can understand that their concern is taking care of their patient....[if] he were 12 years old, I'm sure that it would have been different.
>
> [mother, case #13]: But...it never seemed like there was anybody that would really tell you anything. They may have diagnosed him as that, [schizophrenia] they never told us that. [to husband] They told [young adult], didn't they?
>
> [mother, case #27]: We never saw them and they never saw us. [Young adult] was in [private hospital] for a week and nobody even called us. [father]: which I think they would have if he had been in an automobile accident

Mental health professionals are very concerned about the confidential nature of communications with the patient, which is a cornerstone of the success of individual psychotherapy. However, the data indicate that information parents needed to know in their role as caregivers may have been considered confidential and not shared with parents.

An attitude change toward parents might need emphasis. Professionals need to consider parents as potential caregivers wherever feasible. As caregivers, parents need information in order to provide continuity

of care. Appropriate information is needed by parents not only to increase their potential effectiveness as caregivers, but also to relieve their own distress which may be present because of lack of information. The concept of differentiating confidential information from information which another person has a need to know has recently appeared in the literature:

> A rigid application of the principle of confidentiality cannot serve the needs of young adult chronic patients and their families.... there is a difference between...privacy--with regard to the content and process of the therapeutic relationship--and matters having to do with a young adult's condition, diagnosis, prognosis, everyday management issues, treatment planning and decisions about the future. It is clearly inconsistent to treat parents as outsiders when it comes to sharing "privileged" information, yet to expect them to pick up the responsibility of caregivers. (Pepper & Ryglewicz, 1984b, p. 3)

The data indicate that subjects lacked adequate information about schizophrenia, behavior management, and medications. Appropriate information might have enabled subjects to be more effective care providers. In the interviews, parents did not tend to say, "I need more information about schizophrenia," but when asked if they would <u>like</u> more information on schizophrenia and medications, the subjects nearly always said, "Yes."

<u>Schizophrenia</u>. In general, parents were less concerned about the label, schizophrenia, than expected. Parents had more difficulty than expected in recalling

how they first heard the label. Some of them gradually realized that schizophrenia was what it was. Some of them knew enough about schizophrenia to suspect that their child had it before professionals told them. Examples of subjects perception of the label, schizophrenia, were:

> [father, case #27]: We diagnosed him first. And we told the health and mental health workers that he was schizophrenic, and they said "no"...There is a strong movement not to put a label on people....The educated person is not afraid of anything he can see and analyze and label. He can combat it. You cannot combat ghosts.
>
> [father, case #3]: It wasn't strictly strange to me because I had problems when I was growing up...I had mental problems too [is diagnosed schizophrenic]....I think it really doesn't shock me in any way, it's just like...sugar diabetes...or some physical ailment for the rest of their lives.
>
> [mother, case #19]: [the mental health people didn't tell me] that I know of. But the doctor--my own doctor--told me she was a "schizophreeniac."
>
> [mother, case #15]: We kind of suspected, not <u>knowing</u> that much about schizophrenia....We <u>did</u> think about it.
>
> [father, case #6]: Oh, I think they referred to it as schizophrenia at first, but then I've had it diagnosed by different ones, different ways, and to where I really don't have much faith in any of it....I felt that our family doctor came up with as good a problem solving as anything.
>
> [father, case #23]: He [psychiatrist] gave me a book about it [schizophrenia]. I haven't read it yet...they're usin' big long terms and we don't understand 'em....If he'd sit down and explain what he told us she had--

[father, case #5]: Well, knowing there was an informed diagnosis was a relief....getting good news and bad news....Pinned a name on it. Was a devastating name, too [schizophrenia]....Good news in that it wasn't the worst taboos of all of our culture.....something now that we focused on ....gets it out of the realm of metaphysical....My mind turns to think it's like exorcism would get rid of it.

[mother, case #14]: It's <u>almost</u> better to have a label than to think this disease or this problem that you have no concept of what it is. But, yes it is--it's almost better to have the label.

[father, case #14]: I think I could have understood better, I think. I keep going back to when he was in the special ed. education. I don't think the teachers could really bring themselves to tell us that, "your son has a limited learning." They would say..." if he works on it long enough, he'll get it." Well, and so he'd come home and I'd get angry with him....So I didn't understand. No matter how hard he tried he wasn't going to get it. And geez, that would have been helpful to me, and it caused a lot of stress. I think [they were trying to protect his feelings] and in fact really caused more stress.

[mother, case #26]: I think it's really too bad if someone says "schizophrenia"--others are shocked. I'm always worried about someone misunderstanding--the police, for instance, might use violence if they don't know it's a mental illness. [young adult]: <u>I</u> appreciated the label because you have something to go on --when I was at the hospital, nobody told me what was going on--although it does make me want to give up sometimes with the label of "chronic."...They didn't tell us [that it was schizophrenia]. I looked at the record when someone was out of the [social security] office....It said, "schizophrenia, chronic type."

The data suggest that parents no longer feel that professionals blame them for schizophrenia in their

children. Parents seem less concerned about the label than many professionals. Perhaps professionals consider schizophrenia one of the worst diagnoses possible and would rather consider every other alternative first. However, even after the professionals have diagnosed schizophrenia, the data from this study suggest that they sometimes do not tell parents or that they may have told them, but failed to process the information so that parents had an understanding of the meaning.

The subjects seemed to indicate that, although schizophrenia is a devastating disease, having a label is preferable to distressing uncertainty. Professionals might rethink the matter of a reluctance to inform parents that their young adult son or daughter may have schizophrenia if this is one of the diagnoses being considered. The data from this study indicate that a diagnosis of schizophrenia could be discussed where feasible with parents, and that professionals should process the information so that parents understand important facts.

Support for the findings of this study which indicate that parents should be given information about schizophrenia whenever feasible is found in a report on an educational program for families of patients with schizophrenia:

> Clinicians avoid specifying the diagnosis for a variety of reasons. Some professionals dislike the label "schizophrenia," preferring to

> subsume symptoms under the term "illness." Others shy away from naming the illness because they wish to avoid the patient role for the person who has schizophrenia. It was our experience that relatives welcomed the education--all but one of the relatives before they had received it, and all of the relatives subsequently. (Berkowitz et al., 1984, p. 427)

Behavior management. Subjects expressed concern about how to react to their young adults' distressing behaviors and how to get help for them. Two major issues were identified from the data: (1) these young people were legally adults, although their needs for parental care were more like those of a child, and (2) it was sometimes hard to know whether these behaviors were symptoms of the disease or willful behavior.

Although their children were legally adults, at least 22 of the subjects reported that they were still dependent on parents to pay bills, provide housing, and see that other basic needs were met. A few subjects reported that their young adult children sometimes stated that they were old enough to do whatever they wanted to do. Some parents reported that they had tried without success to control their young adult's money or that they failed to set limits on behavior because of the fear of precipitating angry or violent behaviors. Examples were:

> [mother, case #11]: I was supposed to take care of money, you know. They told me just to give her about $10 just to go out eat, or somethin'. But I used to do it like that, but now she gets mad at me, but it's her money, so

> I don't bother with it. She keeps it now....
> [father]: She spend it all!
>
> [mother, case #8]: I got him his apartment and I was running every day to check on him. And I thought, "This is ridiculous." So I had a phone put in for him. Now see [young adult called about 4 times during interview], when I get home at 5:30, from 5:30 'til 7 or 8 I might get 10 calls....[stepfather]: She talks to him every day....like the first thing in the morning, you tell him....get up and get dressed. And now do this, and do that.

Professionals should be aware that parents are often acting as if their young "adults" are children, because of their lack of independence. Professionals might consider helping parents retain control where appropriate and encourage independence for the young adult wherever possible. It may be helpful to continue supporting parents who support their young adults in appropriate ways, even though the help may not seem age related.

Some behaviors, such as a lack of motivation, which may be a symptom, were dismissed as lazy and willful. Other subjects indicated that they may be particularly susceptible to manipulation on the part of their young adult schizophrenic because of all the attention they required. Family disagreements over the cause of the behavior were reported. Seven subjects mentioned that disagreements on behaviors of the young adult created marital discord. At least 11 other sets of parents argue about how to handle the young adult's behavior. Examples were:

> [mother, case #20]: I really think there's a difference between evil and sick....Everyone would prefer to think that [young adult] can handle his life and his problems and his ideas and emotions, with will-power....And even my husband [at work during the interview] does. And we argue about my son all the time....It creates a lot of problems. On the other hand, my son isn't beyond manipulating, too. Because he knows...Mom's a softer touch than Dad.
>
> [father, case #27]: We used to ask the question--is he not doing what he should because he won't...he's being rebellious, he's being disobedient, whereas he can't do, his brain won't allow him to function....We would go to session after session. I would say is it because he won't or because he can't. The [therapist] would say it is irrelevant. He just isn't....I said that may be but my relationship will be determined whether I believe he can't or he won't.
>
> [father, case #7]: But that, you see that's where you [wife] and I disagree. She says that she thinks [young adult] wants to kill himself and I don't....I've got mad at [him] a few times, maybe I shouldn't have, he called up one time,...he says, "I want to..." I says, "Go ahead and kill yourself if you want to."...of course, I was sorry after I said it. But he never killed himself.
>
> [mother, case #7]: But his brothers and sisters think he's lazy. That he could go out and get a job if he wanted to.

Professionals need to use their theoretical background and skills to help parents manage difficult behavior, explaining what might be causing the behaviors. Professionals need to provide support for parents to regain control of difficult family situations and become more effective decision-makers, with a consequent

elevation of self-esteem. Individual or family counseling or therapy, if desired, could be helpful.

Medications. About 80% of the subjects expressed concern about medications and were usually in a position to influence medication compliance. Most reported having some information about medications, some of which was erroneous. In some cases, parents were against prolonged use of medications; some parents reported stopping the medications when they thought they were too strong without consulting a professional. Several parents reported difficulty in getting their young adult to follow medication prescriptions. Examples follow:

> [mother, case #1]: Our main concern is the way the drugs are handled....I feel like it's a matter of guessing what's the best for them. And there are times when we feel that she's had too many drugs or too little. Right now....she does a great deal of grimacing demonstrates to the point where it is really kind of frightening.
>
> [mother, case #19]: And I know this "naveen" is a very strong medication, because when I was in California this last time....this girl took 5 naveen and 7 Bayer aspirins and she had a cardiac arrest and it killed her....They've [therapists] never told me what she was taking. I've found out by seein'...they give her...this medication in a little envelope...every time they'd give it to young adult, she'd empty it and take the whole thing Friday night. And Dr. [private physician] said "if they don't stop it, she's going to commit suicide or she's gonna get an overdose and it's gonna kill her."
>
> [father, case #3]: They keep sayin' "You need 'em--you need 'em all your life."...well they put me [diagnosed schizophrenic] back on pills...or I probably could a lost my job...I

> get reactions on them...mouth dry...I'd drink a gallon of water a day...so, I got mad one day and I said "Bullshit, I ain't gonna take 'em" ....and this is what I preached to [young adult]...and I was upset they was still givin' her these pills.
>
> [mother, case #26]: One person [at private hospital] --like a social worker--was very enthusiastic and always talked to us--helped a lot--we went up there every day. The psychiatrist would never tell us anything-- would always answer with a question, it was just this one social worker who would tell us about medications, whether he was talking to her or not, etc.
>
> [mother, case #9]: I'm wondering if he got his shot yesterday. if he did, he doesn't act like it....When he gets off his medicine and after he gets through being violent, then he gets to the point when he just stands and stares....And sometimes I have to call the police and have them come get him and take him up for a shot.

Professionals need to be aware of the concern parents have about the effects of medications and the influence they may have on whether or not medications are taken. Medications should be explained as much as possible to those parents who are in a position to influence compliance or observe behaviors. Professionals need to gather information from parents and patients on the effects of the medication and adjust prescriptions accordingly or explain the necessity of continuing the same medication.

Financial Burden

Nineteen subjects described financial stress related to the young adult. Two sets of parents apparently had

no financial problems and five sets of parents did not mention the subject. Parents mentioned the cost of treatment (including Native American treatment), destructiveness by the young adult, and fines and court fees as some of the items difficult to handle financially. Examples were:

> [interpreter for mother, case #20]: She said that they had that nine-day ceremony and that's when he got better....like a thousand people ....helped financially, and with food.... dancers participated in the ceremony... Some requested $40, some $100, the main singer got $1000...So, for that reason they needed that number of relatives to help, or even friends.
>
> [mother, case #19]: She had found another hammer...and she broke this television set, and then I had a great big double thick glass tea table--she just busted the hell out of that, she broke my great big front window and the door....She has the money now to pay for it, but she just don't seem to give a damn whether I get it back or not. The judge ordered her to repay it, but....And I've asked [primary therapist] 2 or 3 times, and she says "Well, we can't give you any money until [young adult] wants to give it to you" but <u>they don't push her</u>, and I don't think until they <u>do</u> push her, I'll ever get it back.
>
> [father case #23]: See, now, another thing, too, now, you know I'm not workin' now and there is just no way that we can pay now, until I get another job....I've had insurance up until now....It was $5,000 for the doctor and $5,000 for the [private] hospital....and that was for...about 3 weeks and 3 days....I've got her on SSI now. And that we done that by ourselves....And you can't believe what we went through to try to even get that for her.
>
> [father, case #6]: When he wants something he calls....He says, "Mom, bring me some flour today." But he doesn't have enough money coming in to handle this apartment. So I'm

> going to have to supplement it, and his mother. ....We're buying him a bicycle for his birthday [his 31st].
>
> [father, case #25]: Well, I haven't ever found out but he checked himself in more or less as a charity patient, I presume. And if we had had the resources, maybe he would have gotten better treatment, I don't know.
>
> [mother, case #25]: So by the end of the year, we had to say that, tell [young adult]...we'd have to stop [private therapy], we couldn't do it any more, pay for the psychiatrist. In fact, we still owe on that bill.

Professionals need to be sensitive to the financial burden which a long term illness can have on a family. Some people are hesitant to ask about the cost of health care. Father number 23 suggested:

> They could say, "Now, if you can't afford this program, here's one that'll take care of it." Then you'll feel like well, I can participate with them people. 'Cause it's--I can't pay the money out right now. I don't <u>have</u> the money. So therefore, [young adult] don't get the medication she needs, I can't pay for it. And they didn't tell me all that other stuff [about SSI]. I had to find this out, myself. And they could do that. They know about that--you know, all the procedures and everything. But when you have to get all of this from scratch and try to locate these things. I'm sure a lot of people give up on it 'cause it's a hassle--to get that SSI....Some people are backward, they don't like to ask.

Professionals should be aware that government entitlements and tax-supported community mental health programs can sometimes help with the financial burden of long term mental illness. These programs should be explained to parents. Assistance in gaining entitlements

for young adults should be provided by staff of the treatment program.

Significance for Nursing

Nurses, particularly psychosocial nurse clinicians, are educated to have a special blend of knowledge and skill which is particularly appropriate for providing professional support to parents of young adult schizophrenics. Critchley and Maurin (1985) refer to a "bridging role" by psychiatric mental health nurses as an opportunity to "bridge gaps" in communication between physicians and patients and between psychiatrists and other mental health professionals (e. g., psychologists and social workers). Community organization experience prepares psychiatric mental health nurses to act "as a bridge between the family and the various services in the community" (Fagin, 1970, p. 163).

Nursing education combines biological science and behavioral science in a holistic approach to the care of patients and their families. Both types of theories are necessary and pertinent to the understanding and management of schizophrenia, since schizophrenia is now assumed to be primarily a biological disease which is influenced in its course by environmental stress and social support.

Psychiatric mental health nurses have an array of practicum experience which could be directly helpful to

parents of young adult schizophrenics. Experience on an inpatient unit is a very important perspective from which to view the problems parents experience in the care of their young adult. In inpatient unit practice, nurses should have developed a fund of knowledge about 24-hour experience with a schizophrenic, desired and undesired effects of medications, and behavior management, which could be useful to parents who may be dealing with the same problems at home.

> Unlike most other health professionals, nurses are there when clients get up and when they go to bed. Nurses interact with clients around the tasks of living--eating, sleeping, getting to appointments, using leisure time, etc. (Wilson & Kneisl, 1979, p. 365)

This perspective gained on an inpatient unit could be used to assist parents. Knowledge of physical, social, and psychological features of daily living for a person with schizophrenia should enable the thoughtful nurse to diagnose problems and enhance strengths in the family in a comprehensive way. For example, agitation, pacing, or active symptoms of hallucinations and delusions during the night would be disruptive in any family. A nurse could suggest changes in medication, diet, fluid intake, activity during the day, family interaction, or bedtime routine.

For psychiatric mental health nurses with a baccalaureate nursing education, family-centered, community

health nursing practicum has provided experience with families in their own homes, which prepares nurses to view families from a perspective not seen in office or institutional settings. Nurses adapt well to working with families on their home "turf" where families are more at ease than in the artificial context of an office setting (Fagin, 1970).

During the 1950s, NIMH was funding master's degree programs in psychiatric nursing and by 1959, 25 such programs were operational in this country (Clayton, 1976). Many public health nurses with experience in psychiatric nursing were attracted into graduate school. However, a split occurred between public health nursing and psychiatric nursing:

> There was considerable controversy and competition within the field as to the particular proficiencies of each approach. It was not a thoughtful collaboration of the two groups that settled the issue. Rather, it was a win for the one and a loss for the other. The psychiatric nursing group won, and in the struggle to define its sphere of practice melded the two content areas, and very clearly staked its claim to psychotherapy. (Fagin, 1981, p. 102)

Psychiatric nursing, by design of NIMH, took its place beside social work, psychiatry, and psychology as one of the "four core mental health disciplines." There was considerable blurring of roles, and all disciplines became psychotherapists. Regular home visits with

mentally ill patients and their families did not become a routine mode of treatment.

Despite the special capabilities of nurses to provide information for parents about schizophrenia and treatment modalities from both a 24-hour care and a community resourse perspective, few subjects reported receiving information and support for themselves directly from psychiatric mental health nurses. Most of the parents, when asked about their experiences with nurses, thought first of nurses on hospital units. Often, nurses in community mental health programs or hospital emergency units were not recognized as to their discipline. One subject mentioned that she did not think the individual in the hospital emergency room was a nurse, because she was not in uniform.

A typical reply to the question, "Could you describe your experiences with nurses?" was that parents had not had much, if any, contact with nurses. A third of the subjects could not remember having talked to nurses at all, but some of them mentioned that nurses were apparently helpful to their young adult children on an inpatient unit. A helpful experience with a nurse was mentioned by 13 subjects and 5 sets of parents reported behaviors of nurses which were not helpful.

This study had a very small sample of parents who had a psychiatric mental health nurse as a primary

therapist for their young adult: only 3 subjects identified a nurse as the primary therapist. Only 1 of the 3 was recognized as a nurse by subjects; she received praise for facilitating communication and support and collaborating with the parents in working toward an independent adjustment in the community for the young adult. Of the professionals who were reported to be helpful to parents in a crisis situation, 3 were known to be psychosocial nurse clinicians by the researcher, but not the parents.

The data indicated that a "gap" in communication exists between psychiatrists and parents. Twenty-one of the subjects reported that they would have liked more access to psychiatrists and that when they did talk to psychiatrists, they sometimes did not know what questions to ask and therefore did not get the information they needed. Nurses may be able to assume a role in "bridging the gap" between parent and psychiatrist.

A routine home visit by a psychiatric mental health nurse could help to establish a relationship with the parents which could facilitate professional support. The visit could also gain information about the cultural environment which affects the patient's adjustment to the mental disorder. Information about past treatment, vocational and social skills of the patient, and other useful information could be gained to help facilitate the

development of an effective treatment plan. Psychiatric mental health nurses should be more involved in supporting parents of young adult schizophrenics than this study indicates.

Strengths and Limitations of the Study

The strengths and limitations of the method of naturalistic inquiry as it relates to the study are discussed here to aid the reader in interpreting the results.

A strength of naturalistic inquiry is that threats to internal validity by intervening elements in the environment are less likely to occur than in a traditional research inquiry because the context of the data is relevant and made a part of the research results (Guba, 1978). In an experimental design, internal validity is seen as the *sine qua non*, with factors in the context of the experimental treatment design and setting controlled as much as possible so that the experimental treatment effect can be elicited (Campbell & Stanley, 1963). Of Campbell and Stanley's classic list of factors relevant to internal validity (history, maturation, testing, instrumentation, statistical regression, selection bias, experimental mortality, and selection- maturation interaction), only instrumentation and selection bias

appear to be pertinent to the naturalistic inquiry method.

The instrumentation was relatively consistent throughout since the researcher conducted all of the interviews. The changes in the interviews over time were a result of a conscious effort to combine the data collection and analysis to enrich the data acquired. Thus, data from later interviews tended to be richer in certain categories of information. For example, the decision was made to add a specific question about what information professionals had made available to parents about medications after this subject had been discussed in some interviews and seemed pertinent to the goals of the research.

Selection bias has been discussed in relation to having professionals select the subjects. The selection of subjects from both rural and urban areas and from various treatment programs could be important in comparing groups, but this type of analysis was beyond the scope of the present study, which was aimed at gaining useful information which could be implemented in any practice setting.

External validity, or generalizability, of naturalistic inquiry is weak in terms of traditional research standards. The experiences of the small sample of parents in this study cannot be said to be representa-

tive of the population of parents of young adult schizophrenics. However, the discovery of potentially useful phenomena, rather than its verification, was the purpose of this research. Guba (1978) noted that "naturally occurring relationships are much more likely to be observed again than those effected under laboratory conditions" (p. 13).

A limitation of the study was that these data could be considered weak in comparison to actual observations of the experience as it occurred over time. The data were parents' perceptions of experience after the experience had occurred, sometimes many years later. However, there was reason to believe that the verbatim transcripts were valid descriptions of the meaning of past experiences to parents at the time of the interview.

Another limitation of the study is that the major data for the study were obtained from one interview with each subject. Repeated interviews might have elicited more in-depth information.

The issue of reliability in a naturalistic inquiry should be addressed. If reliability is viewed as replicability of the study, a naturalistic inquiry method would fall short of a desired standard. Replication of this study is not feasible in the usual sense because of the multiple realities encountered in the experience of the subjects. However, the intent of the research was

not to discover one reality, but to describe a holistic view of the experience that would provide more information than previously available on aspects of this complex experience which might be useful for practice.

An issue of reliability in naturalistic inquiry is the reproducibility of the categories by another competent judge (Guba, 1978). To expect that another researcher with a different background would derive the same set of categories from the raw data of verbatim transcripts is unrealistic. Guba suggested that a competent judge should examine the raw data to determine the "fit" with the researcher's categories as one indication of reliability (p. 71).

As Guba suggested, an "audit" was accomplished for this research project by having a competent judge review a random sample of the unanalyzed interviews together with the set of categories derived by the researcher. The competent judge chosen to assist with this project, a psychosocial nurse knowledgeable about the schizophrenic experience, reviewed a random sample of 10 verbatim transcripts and provided helpful suggestions which were used in the data analysis.

The issue of objectivity, or neutrality, needed to be addressed in what is essentially subjective research in that the opinions of individuals were being sought. Whether doing traditional scientific research or

naturalistic inquiry, "data should be reliable, factual, and confirmable" (Guba, 1978, p. 74). The verbatim transcripts in this study tended to meet this criterion as there was reason to believe that parents were expressing an account of events and feelings as they perceived them at the time of the interview, which was in keeping with the aim of the research.

Other threats to neutrality were addressed. An effort was made to make the researcher's bias explicit. The interviews were designed to utilize her experience in interacting with parents in their own homes and her ability to be supportive without unduly influencing the response. The researcher was also conscious of the need to be open and fair in her responses to the data acquired in the interviews.

This research project utilized four of five strategies for controlling bias suggested by Diler (1982): (1) an attempt was made to make the researcher's perspective explicit, (2) competitive views (e. g., helpful, not helpful) were sought, (3) subjects previously unknown to the researcher were sought, and (4) an attempt was made to be an unobtrusive presence in the interview as much as possible. The fifth suggested strategy, using research teams in data collection, was not met.

A strength of the research in comparison to presently available information was that the sample of

parents was mostly individuals who were not involved in organized family support groups and who had a lower average annual income than previously-studied groups. Thus, a process of professional support for people who do not tend to become involved in organized groups could be suggested from the results of this research.

A limitation of this research study was that three of the interviews may have been affected by the fact that the young adult's therapist made the appointment with the subjects or participated in the interview as an interpreter. This approach may have precluded reports of any nonhelpful behaviors on the part of those clinicians as no nonhelpful behaviors were reported in these two interviews.

5. TOWARD A THEORY OF PROFESSIONAL SUPPORT

The purpose of the research study was to discover useful information which could be implemented in practice. Suggestions toward a proposed theory of professional support for parents of young adult schizophrenics have been derived from background information and research, from the researcher's own experience, and from the data of this report. Processes for informing and involving parents in the care of their young adult schizophrenic is suggested.

A Model of Professional Support

A conceptual model of professional support which fosters mutual support among professional, patient, and parents was developed for this study. The key element in the model for the purpose of this study was professional support and information for parents of young adult schizophrenics.

The conceptual model was adapted from Doherty and Baird (1983), who applied a family system theory to the matter of patients' compliance with a treatment regimen in the general health care field. They conceptualized a "triangle" of communication among patient, physician, and

family, all of whom need to understand and concur with the treatment regimen and be motivated to support it in order to increase the likelihood that compliance with treatment will be successful (p. 141). The physician at one point on the triangle supports both the patient and the family, with the family in turn supporting the patient.

An adaptation of Doherty and Baird's conceptual model envisions a triangle with the three corners occupied by a professional, a young adult schizophrenic patient, and the parents of the young adult (please see Figure 1). For purposes of the present study, the key transactional ingredient in the triangle was the professional support provided by the nurse or other professional to parents. The assumption was that parents, with professional support to alleviate their own stress, may in turn be more effective in providing social support to their young adult children and assisting them to participate positively in the treatment and rehabilitation program. The concept of support along all sides of the triangle includes two-way communication as a way to provide information and to validate the interaction and its effect on the other person. The two-way arrows illustrate this concept.

In order to accomplish professional support for parents, the psychiatric mental health nurse or other

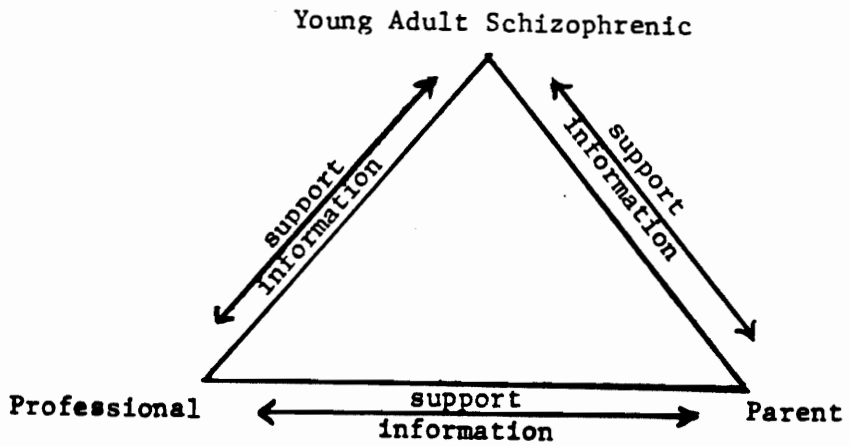

Figure 1. A model of professional support for parents.

professional must have an understanding of the relevant theories which have been discussed. A knowledge of the genetic theories of schizophrenia is important information which helps shape the attitude of professionals toward parents as innocent of causing the disease. Parents may need to know about the likelihood of occurrence of schizophrenia in other family members or future generations. Knowledgeable professionals could answer questions of parents or refer them to genetic counseling.

The biochemical theories are an important component of pharmacotherapy, the specific treatment for schizophrenia. Parents need to know practical information about the expected effects of medications, that individuals react differently to each medication, and that there may be undesirable effects which may interfere with

compliance and should be reported. Parents need appropriate information about the medications prescribed, the expected effects, and the potential for modifying prescriptions as clinically indicated.

Psychodynamic and system theories are important in helping professionals interact effectively with parents as individuals in a specific family and community context. Labeling theories explain some of the stigma and other negative effects of the attitude of society toward families with schizophrenic members. Professionals need to be careful that they individualize their interactions with parents and do not fall back on earlier concepts that parents are always dysfunctional in schizophrenia.

A knowledge of theories of stress and social support may enable the professional to provide information for parents about the effect of stress on symptoms of the disease. Professional support for parents can decrease parental stress and increase parents' ability to provide support for the young adult.

An understanding of the theory of hierarchical incongruity might assist the professional toward helping parents to regain control in the family where appropriate. Despite the symptoms of schizophrenia, the young adult needs appropriate parental guidance toward an adult life with as much independence as feasible.

Assumptions of the proposed theory of professional support are: (1) that parents are usually primary caregivers for the young adult schizophrenic, (2) that being a parent of a young adult schizophrenic is stressful, (3) that parents need professional support in order to be more effective caregivers, and (4) that professionals need to provide professional support for parents who are in a role as caregivers.

The model does not adequately explain the role differentiation of each occupant of a corner of the triangle. The young adult is the patient and the recipient of treatment and support, but is not to be considered a passive recipient. The young adult possesses information about his or her experience which parents and professionals need to know.

The parent has a fund of experiential knowledge of the patient and should be considered in the role of a primary resource for care and support (both social and financial) when feasible. The parent also has information about the types and effects of past treatment and care which could be useful and should be shared with the professional.

The professional has a role as the authority for information about schizophrenia, for assessing the needs of the patient and the parents, and for initiating and carrying out the treatment and care plan. Professionals

also collaborate with other professionals and other community agencies in planning and carrying out the treatment program.

Mutual Support

A key issue in this research project is a continued need for professionals to shift their focus from "treatment" to "support" for parents of young adult schizophrenics. This research supports the notion that parents are no longer blamed directly for the development of schizophrenia in their young adult and are no longer considered dysfunctional on the sole basis of the having a schizophrenic offspring. Parents are being recognized in the literature as primary caregivers. However, the data from this study indicate that professionals are not regarding parents as primary caregivers and that parents need, but are not getting sufficient support and information to fulfill this role.

It is important that professionals keep in mind that two-way communication is essential if the relationships are to provide a climate for both positive and negative feedback as information is processed by each individual. Examples from the data of this report illustrate each direction of support which makes up the model.

Parent supports professional:

[mother, case #1]: And she's [nurse therapist] very strict with [young adult], but she needs

> to be; and everything she tries to do, we back her up all the way.

Young adult patient supports parents:

> [mother, case #1]: We've been doing quite a bit of traveling, so we've shifted the responsibility for the house...to [young adult], so that she brings in the paper, waters the plants, and does whatever is necessary around here, and she's been very good about that.

Young adult patient supports professional (case #5):

A young adult requested input into this report in addition to giving his consent for his parents to be interviewed. He said that one time he had a "shuffle" which frightened him. He was really upset because of what his mind told him was preventing him from being able to move his feet like he should, and staff had to restrain him. He said that had he known this was a medication effect, he would not have been so upset and it would have helped both himself and the staff. He wanted professionals to know that it would be helpful to inform patients about possible undesired effects of medication.

Professional supports parents:

> [mother, case #14]: If [young adult] doesn't show up for his shot....[nurse therapist] calls and then we say, "OK, [young adult] go. You forgot to get your shot....if you don't take the shot... you're out [medications are a condition for continuing to live at home].

Parent supports young adult:

[mother, case #8]: I don't clean it for him but I go over....I just tell him, "OK, well you better do this and this." And I am very proud of the way he's keeping that apartment.

Professional supports young adult:

[mother, case #7]: And there was a couple of nurses that went over to [young adult's] trailer one night and talked to [him] because he said he was paranoid.

The parent and the patient are seen as capable of providing information and social support to some extent in the model of a three-way supportive relationship among patient, parent, and professional. The role of parent as a caregiver is influenced by the amount of social support available, the amount of emotional overinvolvement with the young adult, the cultural context of the family and community, and the amount of understanding of the disease, treatment processes, resource availability, and medications. The young adult's ability to provide information and support is influenced by the symptoms of schizophrenia, by other conditions, and by his or her cultural orientation and level of motivation.

In order to provide effective professional support, professionals must be knowledgeable about schizophrenia, examine their own beliefs about the parents of schizophrenics, approach parents with an open attitude about their ability to participate effectively in the treatment

process, and gain an understanding of the cultural context of schizophrenia in the family.

The model of mutual support does not deal with the treatment aspects of the professional role. The person providing professional support to parents might also be the primary therapist for the young adult. The professional could be in private practice, a hospital employee, or a community mental health center employee. The primary therapist could take the time to provide professional support, including information, to the parents, or could arrange for parents to obtain needed support and information from other professionals, family support groups, and natural support groups.

Therapists face the potential of creating misunderstandings with the patient when a continual relationship with parents is established. In order to avoid this type of situation, Lamb (1976) suggests that contact with parents wherever feasible should be with the patient present: "When the patient is not included, his fantasies as to what has happened 'behind his back' run wild" (p. 27). The triangular model of professional support suggested in this study is intended to emphasize mutual support and clarity of communication wherever possible among the young adult, parent, and professional.

Conclusions and Recommendations

The purpose of the research study was to discover useful information which could be implemented in practice. Information has been presented toward a proposed theory of professional support for parents of young adult schizophrenics which has been derived from background information and research, from the researcher's own experience, and from the data of this report. The findings of the study indicate that parents need to be recognized as primary caregivers and provided with additional information and professional support to be more effective caregivers. Processes for implementing the proposed theory of professional support in practice are suggested below.

View Parents as a Potential Care Resource

Parents of young adult schizophrenics should be considered a potential care resource whenever feasible. In order to be effective caregivers, parents need professional support.

Foster a Climate of Sensitivity and Esteem

Individualized attention should be given to needs of parents of young adults schizophrenics to be treated with respect and kindness and be considered as a resource of

information and support. Professionals should be sensitive to the enormous stress which parents of young adult schizophrenics experience, especially at the onset of the disease. Professionals might be alert to indications that social support for parents may be restricted in some way because of the schizophrenia of their child.

Develop a Continual Relationship with Parents

The data indicate that parents of young adult schizophrenics could benefit from a continual relationship with a professional beginning at the onset of schizophrenia when they may need help more than at any other time. Parents need to have a professional to turn to for information and support over the long period of time that the young adult is in treatment.

Parents have a role in continuity of care. They need to know about any change in therapist or treatment program if they are a primary caregiver. Professionals might assist in introducing parents to a new therapist when feasible. Parents can be a resource for information about any previous treatment.

Provide and Process Appropriate Information

Appropriate information should be provided to parents who are in a role as caregiver or are concerned

about the immediate condition of the young adult. Such information should include, but not be limited to, information about the diagnosis, symptoms, medications, and current condition of the young adult. Professionals should also make available any appropriate written information about schizophrenia and take the time to process this information with parents.

The issue of confidentiality versus the "need to know" should be given careful attention when providing information to parents of young adults with schizophrenia. Parents may need to know whatever is not confidential and could serve to reduce their level of stress or improve their ability to be useful in the treatment process. Appropriate information may help parents to be more effective caregivers and improve treatment outcome.

Professionals should routinely orient parents to the treatment system, with information about how to contact the psychiatrist and how other professionals can help. The nature of the treatment program and any rules which might affect parents need to be explained to them.

Encourage Family Support Groups

Professionals might inform parents about opportunities to join organized family support groups and avail themselves of other social support systems. Some parents might take advantage of the opportunity to join an

organized group, some might not be inclined to join for various reasons, and some might be encouraged to attend an educational session where they would not need to take an active part in sharing their problems.

Assist Parents with Behavior Management

Professionals might be alert for opportunities to assist parents in dealing with difficult behaviors of the young adult, helping them to sort out which behaviors might be symptomatic and which might be manipulative or due to other causes. Efforts by both professionals and parents should be made to facilitate social and vocational rehabilitation for young adults to the extent feasible. Residential alternatives should be facilitated where feasible and appropriate. A movement toward independence for the young adult with schizophrenia could free parents to seek a more satisfying social life for themselves.

Consider Routine Home Visits

A routine home visit by a psychiatric mental health nurse, social worker, or other therapist might be considered. The home visit might be most helpful as near the onset of the disease as feasible. The purpose might be to explain the treatment program, listen to parents' concerns, get information for the treatment plan, and provide information to parents. A home visit on the

parents' own "turf" might help to establish an effective relationship which could improve treatment outcome and decrease parents' stress.

Educate Professionals to Work with Parents

Mental health professional education programs should provide more training for professionals about how to gain the cooperation of parents as an ally in the treatment process. Educators might consider the reported success of psychoeducational models and supportive home visits when developing curricula. These and other approaches to supportive family interventions with schizophrenics could be included in basic professional education and in continuing education programs.

Consider Further Research

Further research is needed to gain more information about the experience of parents and other family members and their need for professional support. This study might be replicated with the inclusion of the young adult patient in interviews done in the home. A larger sample is needed to make additional conclusions about the type of support needed. Studies could be done in different cultural settings.

The cost-effectiveness of the processes of professional support suggested in this study need to be tested.

A research design might test whether or not expensive treatment such as inpatient and emergency services might be reduced by attention to the effectiveness of parents as caregivers.

APPENDIX A

INFORMED CONSENT FORMS

Informed Consent Form - Patient

The purpose of this study is to help nurses and other mental health care providers to better understand the feelings, experiences, and needs of parents of young adults who have a serious mental illness. It is hoped that this information will help to describe new ways that nurses and other professionals can assist parents.

Your participation in this study is completely voluntary. Your care and treatment will not be affected in any way by whether or not you participate.

Your participation would involve giving your permission for a nurse to contact your parents and to record information from your clinical record. The nurse would contact your parents to ask for an appointment to talk with them about their experiences and what might have been helpful to them in understanding the disease and helping you to cope with it.

All information will be kept strictly confidential. Yours or your parents' names will not appear in any report. The nurse will record information from your clinical record without using your name on any of the documents. She will keep a separate list of names which will not be available to anyone else.

You will be one of about 30 young people taking part in a research study which may provide help to some others in the future.

You may talk with the research nurse, Marilyn Park, about the procedure for the research if you have any questions. She can be reached at 533-5783 or your therapist can notify her that you would like to talk to her.

Your help with this project is very much appreciated.

I have read the above information and have discussed any questions which I had about the study. I have received a copy of this form. I now give my consent to have the research nurse contact my parents and to record information from my clinical record for this study.

_____ _____

signed date

_____

witness

Informed Consent Form - Subject

The purpose of this study is to help nurses and other mental health care providers to better understand the feelings, experiences, and needs of parents of young people with serious mental illness. It is hoped that this information will help to describe new ways that nurses and other professionals can assist other parents of young people with a mental illness.

Your participation in this study is completely voluntary. The care and treatment of your son or daughter will not be affected in any way by whether or not you participate. If you do agree to participate, you may decide to withdraw your participation at any time or to not answer any of the questions. You will be one of about 30 sets of parents to be interviewed.

Your participation will involve talking with a nurse in your home at a convenient time for you. The interview is planned to be no more than one and one half hours. another interview may be arranged if you and the nurse researcher feel that it would be helpful. You will be asked to share your experiences, feelings, and what you feel was or was not helpful to you in regard to the care and treatment of your child. With your permission, the interviews will be tape recorded.

All information will be kept strictly confidential. Your name will not appear on any of the papers with information you give to the nurse or on any reports of the project. A separate list which will identify you by code number will be kept by the nurse researcher. This list will not be seen by anyone else and you will not be identified in any way in the written report.

Answering questions or talking about painful experiences may be difficult for you at times. However, you will be participating in a research study which may provide help to some others in the future.

You may call the research nurse, Marilyn Park, at 533-5783 (work) or 278-9574 (home) or the University Medical Center Institutional Review Board at 581-3655 at any time with questions about the research project.

I have read the above information and have discussed any questions which I had about the study. I now give my consent to be interviewed by the nurse to participate in this study.

_____ _____

signed date

_____

witness

APPENDIX B

INSTRUMENTS AND MEASURES

Demographic Information - Both Parents

(A) Present living arrangements of your son/daughter with schizophrenic/schizoaffective disorder:

____(1) Lives at home with parent(s)
____(2) Lives with another relative Who?_____
(relationship)
____(3) Lives alone Where?_____(city)
____(4) Lives with friends Where?_____
____(5) Lives in residential care facility Where?_____
____(6) In hospital Where?_____
____(7) In nursing home Where?_____
____(8) Other Describe_____
____(9) Unknown When last seen?_____

(B) How many other children do you have)_____
(C) How many are living at home with you?_____

(D) What are the present sources of financial support or income for your son/daughter?

____(1) SSI
____(2) Medicaid
____(3) Social Security
____(4) Family Support
____(5) Health Insurance
____(6) Savings
____(7) Employment
____(8) Public Assistance (Welfare)
____(9) Other:_____

(E) What annual/yearly income range would best describe your family?

____(1) $5,000-10,000
____(2) 10,000-20,000
____(3) 20,000-30,000
____(4) 30,000-40,000
____(5) 40,000-50,000
____(6) over 50,000

Demographic Information and Rating Scales - Father

Age:____

*Race:____(1) Caucasian
____(2) Black
____(3) Spanish American
____(4) Native American
____(5) Oriental
____(6) Other_____

Education:____(1) None
____(2) 1 - 6 grades
____(3) 7 - 11 grades
____(4) 12 - High school grad.
____(5) 13 - 15 College Grad & beyond

(1) Have you been involved with a Family Support Group, e. g., Utah Alliance for the Mentally Ill, Salt Lake County Alliance, Catalyst, etc.? (Please circle the answer which most nearly describes your involvement)

1	2	3	4
Never	Some	Moderate	Active member

(2) Have you participated in an educational series of classes about schizophrenia led by professionals?

1	2
No	Yes

(3) How do you feel about your son/daughter's living arrangements?

____(1) Strongly satisfied
____(2) Satisfied
____(3) Neither satisfied nor dissatisfied
____(5) Strongly dissatisfied

Follow-up: what would you prefer?

*In the report, data were more appropriately organized into "Ethnic groups," of which there were only 3: Anglo American (instead of Caucasian), Native American, and Spanish American.

Demographic Information and Rating Scales - Mother

Age:____

*Race:____(1) Caucasian
____(2) Black
____(3) Spanish American
____(4) Native American
____(5) Oriental
____(6) Other_____

Education:____(1) None
____(2) 1 - 6 grades
____(3) 7 - 11 grades
____(4) 12 - High school grad.
____(5) 13 - 15 College Grad & beyond

(1) Have you been involved with a Family Support Group, e. g., Utah Alliance for the Mentally Ill, Salt Lake County Alliance, Catalyst, etc.? (Please circle the answer which most nearly describes your involvement)

1	2	3	4
Never	Some	Moderate	Active member

(2) Have you participated in an educational series of classes about schizophrenia led by professionals?

1	2
No	Yes

(3) How do you feel about your son/daughter's living arrangements?

____(1) Strongly satisfied
____(2) Satisfied
____(3) Neither satisfied nor dissatisfied
____(5) Strongly dissatisfied

Follow-up: what would you prefer?

*In the report, data were more appropriately organized into "Ethnic groups," of which there were only 3: Anglo American (instead of Caucasian), Native American, and Spanish American.

Data Sheet - Young Adult

Subject # _____
Facility # _____
Sex _____
Age _____

Date of Diagnosis _____
Comment_____
_____
_____

Diagnostic criteria for schizophrenic disorder (DSM III, p. 188-189)

A. At least one of these:
(1) bizarre delusions ___
(2) delusions-somatic, grandiose, religious nihilistic, or other without persecutory or jealous content ___
(3) persecutory or jealous delusions and hallucinations ___
(4) auditory hallucinations, either with running commentary or 2 voices conversing ___
(5) auditory hallucinations of more than 2 words not related to depression or elation ___
(6) illogical thinking, poverty of speech and ___
(a) blunted, flat, inappro. affect
(b) delusions or hallucinations
(c) catatonic or other grossly disoriented behavior

B. Deteriorated social functioning ___

C. Duration at least 6 mo. which could include prodromal or residual phase, with present Sx ___

Treatment modalities _____
_____
Other pertinent information _____
_____
_____
_____
_____
_____

Interview Guide

(Recorded interview - approximate time 45-60 minutes. Ask permission to record - name will be confidential and no information which could identify them will appear in the final paper - I will keep the names and identifying numbers, no one else will see that list).

Transition: I would like to know more about the experience of being a parent of a young person who has a serious mental illness. I have some specific topics and questions, but I would also like to have you talk freely about your experience and about anything you feel is important - about how your daily living has been affected and about your experience with health and mental health systems of care and treatment. I believe that information from you and other people in your situation may help nurses and other professionals to be more helpful to families in the future. I expect that we will talk for about 45 minutes. We may decide that it would be helpful to make another appointment for me to come back and visit with you at a time when it is convenient for you.

1) EARLY EXPERIENCES WITH SCHIZOPHRENIA.

Would you describe how you learned that your son/daughter has a mental illness?

Did they use any kind of label for your son/daughter's mental illness?

What were your thoughts and feelings about the label of this disease?

What are your thoughts and feelings about the label today?

2) ROLE OF FAMILY MEMBERS AND FRIENDS.

Could you tell me about how other family members reacted to the disease? How do they react now?

Can you think of some examples of what other family members did or said when they learned of the disease/schizophrenia?

Have family members been helpful and available?

Can you think of anything they did that was not helpful?

Could they have been more helpful? How?

Could you describe how any of your close friends reacted to learning of the disease/mental illness/schizophrenia?

How have your friends or others helped?

Can you think of anything they did that was not helpful?

Could they have been more helpful? How?

3) ROLE OF PROFESSIONALS.

Would you describe how you decided to consult a doctor or other professional person?

Without mentioning any names, could you describe the ways that you contacted professionals for help and how those people responded?

Were they helpful and available? How?

Is there anything they did or did not do that was not helpful? Would you describe these things?

Could you tell me more about your experiences with nurses?

Could doctors, nurses, or others have been more helpful? How?

4) INFLUENCE ON FAMILY LIFE.

What changes in daily activities were made when you first learned that your son/daughter has a schizophrenic /schizoaffective disorder?

How does this disease affect your daily activities today?

How do you feel this disease has affected your role as a parent to your son/daughter? to your other children?
Would you describe a typical day in your family life when your son/daughter is at home? not at home and you feel he/she is safe? not at home and you feel he/she may be in trouble?

5) NEIGHBORHOOD AND COMMUNITY CONTEXT.

How have neighbors reacted to your son/daughter's illness?

How have they been helpful? not helpful?

How have other groups in the community reacted to your son/daughter's illness? church groups and individuals you know at church? other social or professional groups? people you know at work?

How have any of these individuals been helpful? not helpful?

6) OTHER PERTINENT INFORMATION

Is there anything else you think of that you could tell me about how you feel about the experience of having a schizophrenic/mentally ill son/daughter?

Is there any advice you would give to other parents in your situation as you look back on your experience?

Is there anything you would like to have nurses, doctors, or others do to make it easier for you to deal with this difficult problem of having a mentally ill young person in the family?

Categories for Organizing Information

I. Stressful Experiences
- A. Before 1975
- B. 1975 to 1980
- C. After 1980
- D. Up to 2 years since diagnosis
- E. 2 to 6 years since diagnosis
- F. Over 6 years since diagnosis

II. Professional Treatment Programs
- A. Before 1975
  - 1. Helpful
  - 2. Not Helpful
- B. 1975 to 1980
  - 1. Helpful
  - 2. Not Helpful
- C. After 1980
  - 1. Helpful
  - 2. Not Helpful
- D. Up to 2 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- D. 2 to 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- F. Over 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful

III. Professional Behaviors
- A. Before 1975
  - 1. Helpful
  - 2. Not Helpful
- B. 1975 to 1980
  - 1. Helpful
  - 2. Not Helpful
- C. After 1980
  - 1. Helpful
  - 2. Not Helpful
- D. Up to 2 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- E. 2 to 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- F. Over 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful

IV. Labels

Schizophrenia
- A. Before 1975
  - 1. Helpful
  - 2. Not Helpful
- B. 1975 to 1980
  - 1. Helpful
  - 2. Not Helpful
- C. After 1980
  - 1. Helpful
  - 2. Not Helpful
- D. Up to 2 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- E. 2 to 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful
- F. Over 6 years since diagnosis
  - 1. Helpful
  - 2. Not Helpful

Other Label

A. Before 1975
   1. Helpful
   2. Not Helpful
B. 1975 to 1980
   1. Helpful
   2. Not Helpful
C. After 1980
   1. Helpful
   2. Not Helpful
D. Up to 2 years since diagnosis
   1. Helpful
   2. Not Helpful
E. 2 to 6 years since diagnosis
   1. Helpful
   2. Not Helpful
F. Over 6 years since diagnosis
   1. Helpful
   2. Not Helpful

V. Behaviors of Potentially Supportive Individuals
   A. Confidant
      1. Helpful
      2. Not Helpful
   B. Acquaintance
      1. Helpful
      2. Not Helpful
   C. Stranger
      1. Helpful
      2. Not Helpful
   D. Knowledgeable Person
      1. Helpful
      2. Not Helpful

VI. Behaviors of Potentially Supportive Group Members
   A. Family
      1. Helpful
      2. Not Helpful
   B. Church
      1. Helpful
      2. Not Helpful
   C. Private Hospitals
      1. Helpful
      2. Not Helpful
   D. Schools
      1. Helpful
      2. Not Helpful
   E. Law Enforcement
      1. Helpful
      2. Not Helpful
   F. Courts
      1. Helpful
      2. Not Helpful
   G. Social Services Agency
      1. Helpful
      2. Not Helpful

H. Media
    1. Helpful
    2. Not Helpful
J. Family Support Groups
    1. Helpful
    2. Not Helpful

VII. Advice to Other Parents

VIII. Advice to Professionals

IX. Ways Parents Could Support Professionals

APPENDIX C

ADDITIONAL DATA

Demographic Variables of Young Adults with a Schizophrenic Disorder

N = 27

Variable	Number of years		
	Mean	Mode	Range
Age at time of interview	26.4	29	19 - 34
Age of onset of schizophrenia	19.2	19	14 - 24
Time since diagnosis	7.2	8	1 - 16

Variable	Frequency
Ethnic Group:	
Anglo American	23
Spanish American	1
Native American	3
Living Arrangement:	
At home with parents	16
With spouse	1
Spouse and in-laws	1
Alone	4
With friends	2
Residential facility	2
Nursing home	1
Experience in Jail:	
Yes	11
No or not mentioned	16
Reported violent behaviors:	
Suicide attempts	14
Destructive (property)	15
Harmful to others	11
Other conditions:	
Drug and alcohol abuse	17
MR or MBD	7
Personality disorders	12
Other physical disorder	10

Variable	Frequency
Financial support: (may be more than one)	
SSI	14
Medicaid	8
SSDI	9
Parents	7
Savings	1
Employment	3
Public Assistance	1
Medicare	1
Experience in Hospitals:	
Public & private (state or federal)	17
Private only (same community)	10
Stressors at onset:	
Parent died	4
Grandparent died	2
Parents divorced	3
Church mission	2
Marriage	1
Divorce	3
Birth of a child	1
Sex:	
Male	16
Female	11

Demographic Variables of Parents

Sets of Parents: N = 27
Mothers: N = 27
Fathers: N = 19
Total Individual Parents: N = 46

Variable	Mean	Range
Age of Mothers	53.2	34-70
Age of Fathers	55.5	44-72
No. other children	3.9	1-10
No. others @ home	1.2	0-4

Variable	Frequency		
Ethnic group:	M	F	
Anglo American	22	18	
Native American	3	1	
Spanish American	2	0	

Variable	Frequency
Family income range:	
$ 5,000 - 10,000	6
10,000 - 20,000	4
20,000 - 30,000	10
30,000 - 40,000	4
40,000 - over	0
Not reported	3
Mothers:	
Natural mothers	24
Adoptive mothers	2
Stepmothers	1
Total	27
Fathers:	
Natural fathers	16
Adoptive fathers	2
Stepfathers	1
Total	19
Religion:	
LDS	19
Catholic	1
Baptist	1
Episcopalian	1
Pentecostal	1
Other protestant	1
Unknown or no pref.	3
Total	27

Education:	M	F
None	1	0
1-6 grades	2	1
7-11 grades	1	2
Hi school grad	17	5
College,voc.ed.	3	7
College grad & up	1	3
Not reported	2	1
Family support group involvement:	M	F
Never	15	15
Some	5	4
Moderate	3	0
Active member	3	0
Not reported	1	0
Satisfaction with living arrangement:	M	F
Strongly satisfy	2	3
Satisfied	10.5	9.5
Neither	7.5	2
Dissatisfied	6	3
Strongly dissat.	0	1.5
Preferred living:	M	F
More structure	6	3
More independent	6	3

Frequency Distributions

First Community Resource Contact which Resulted in Treatment	
Variable	Frequency
CMHC	6
Private hospital	7
Law enforcement or Court	4
Private practitioner	5
Family physician	2
Religious leader	1
Public hospital	1
Unknown	1
Total	27

Judged High EE	
Young adult @ home	12
Not at home	2
Total	14

Researcher met Young Adult	
Yes	17
No	10
Total	27

Researcher had met parent before	
Yes (mothers only)	3
No	43
Total subjects	46

Availability of fathers	
Complete interview	15
Part of interview	4
Not interviewed	4
In nursing home	1
Total	24

Young adults interviewed	
Complete interview	2
Part of interview	3
Total	5

Primary Rx Identified by Parent	
Category	Frequency
Yes	21
No	6
Total	27

Uncoordinated Treatment Systems	
Yes	23
No	4
Total	27

Subjects social life less	
Yes	14
No	5
Not mentioned	8
Total	27

Consent form signed by young adult	
Yes	32
No	6
Total	38

Nurses helpful?	
Helpful	13
Not helpful	5
No contact	9
Total	27

Young adult needs job or training	
Yes	15
No or not known	8
Total	23

(4 in sheltered work or vocational training)

Parent has had Indiv. Rx	
Yes	7
No or not known	39
Total (mothers & fathers)	46

Age of Onset
Males: N = 16
Females: N = 11

Age	Frequency	
	Males	Females
14	0	1
15	1	0
16	0	1
17	3	0
18	1	2
19	4	5
20	1	0
21	2	0
22	3	1
23	1	0
24	0	1
Total	16	11

Time Since Diagnosis

Years	Frequency	
	Males	Females
1	1	2
2	1	0
3	0	0
4	3	0
5	1	1
6	1	1
7	0	2
8	1	3
9	3	0
10	2	1
11	1	1
12	0	0
13	0	0
14	1	0
15	0	0
16	1	0
Total	16	11

Age @ Time of Interview

Age	Frequency	
	Males	Females
19	0	1
20	0	1
21	0	1
22	2	0
23	1	0
24	2	1
25	2	1
26	1	0
27	0	3
28	1	0
29	3	2
30	1	0
31	2	0
32	0	1
33	0	0
34	1	0
Total	16	11

Time-Since-Diagnosis

Time Frame	Frequency
<2 yrs.	4
2 - 6 yrs.	7
>6 yrs.	16
Total	27

Experience in Time-Since-Dx

Time Frame	Cumulative Frequency
<2 yrs.	27
2 - 6 yrs.	23
>6 yrs.	16

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